View metadata, citation and similar papers at core.ac.uk

brought to you by CORE

provided by University of Queensland eSpace

THE UNIVERSITY OF QUEENSLAND

AUSTRALIA

Outcomes of an Intensive Comprehensive Aphasia Program

Edna Marie Babbitt

M.Ed., CCC-SLP, BC-ANCDS

A thesis submitted for the degree of Doctor of Philosophy at

The University of Queensland in 2017

School of Health & Rehabilitation Sciences

Abstract

Intensive comprehensive aphasia programs (ICAP) have increased over the last decade in the US and abroad. The increase in the number of clinical programs has outpaced the research that is necessary to establish the efficacy and effectiveness of these specialized treatment programs. The ICAP model incorporates principles from neuroplasticity, that is, intensive treatment provides a platform for the massed practice and repetition required to change the brain. It also incorporates comprehensive treatment that addresses not only impairment-based language deficits but also personal goals related to participation. Programs which offer intensive comprehensive treatment can provide up to 120 hours of treatment over several weeks (e.g., six hours a day, five days a week for four weeks). ICAPs are different from other types of aphasia services which generally provide two to three hours of therapy a week. This thesis examined one ICAP in depth to describe the structure, process, and outcomes using Donabedian's model of health care evaluation. This thesis also described the experiences of the ICAP from the perspectives of the primary stakeholders.

Study One (Chapter Two) was a retrospective quantitative study using behavioral measures from an existing database that documented the outcomes of participants with aphasia. It found that first-time participants improved significantly in impairment- and participation-based measures, demonstrating moderate to large effect sizes. Participant characteristics were examined to determine if improvements were related to age, time post-onset, or type and severity of aphasia. None of these factors had an impact on the amount of change measured. Given that some participants did not make significant gains on a primary outcome measure, the Western Aphasia Battery – Revised Aphasia Quotient (WAB-R AQ), Study Two (Chapter Three) examined whether participant characteristics at baseline could predict who would make significant gains on the WAB-R AQ. Age and months post-onset were significantly different between the responder and the non-responder groups. Those who showed most gains on average were younger and a longer time post-onset. A logistic regression was performed and results indicated that only age (younger participants) predicted who would respond to treatment. Time post-onset, type and severity of aphasia, naming, non-verbal cognition, and communication confidence did not show significance in a predictive model.

Studies Three and Four were qualitative studies involving interviews with therapists (Chapter Four) and people with aphasia and their families (Chapter Five). Both studies were

conducted using a phenomenological approach which allowed for the interviewees to describe their experiences in a semi-structured interview. The clinicians described the intensity of the therapy, the rewards, and challenges of the program. Therapists also considered that the ICAP model of service delivery had several positive benefits for them, but acknowledged that the intensity of therapy was challenging for them personally. The participants and family members also described the intensity of the therapy, but in addition, emphasized the improvements they saw and the relationships they developed. Many of the stakeholders felt the treatment was tiring, but worth it. The relationships they developed were important. Interestingly, the participants and family members generated themes regarding outcomes in areas that were not measured, such as psychosocial health and physical stamina. The themes were intertwined and it was the combination of the intensity of the therapy in a short time period in the same physical environment that led to the ICAP providing a "therapeutic milieu."

The concluding chapter (Chapter Six) synthesized the findings from all studies and using Donabedian's model described how the structure and process of the ICAP may have impacted upon the outcomes. In examining the structure of the selected ICAP, many factors contributed to effective treatment. Structural factors included operation of the program in an off-site office building, extensive staff training, self-selected staff and participants, greater number of hours of therapy per day, and twice daily staff meetings. Processes that contributed to successful outcomes included the intensive therapy (providing more days, hours, and therapy tasks), extensive pre- and post-treatment evaluations, and use of a wide range of evidence-based treatments. Using both retrospective quantitative and prospective qualitative methods to examine outcomes, this thesis demonstrated that participants made significant improvements on standardized tests and the primary stakeholders reported significant improvements and positive gains.

This thesis describes how the ICAP provided an environment that not only provided intensive therapy, but was a physical space that offered opportunities for improved physical stamina and activities of daily living and psychosocial support. Future research may further identify the active ingredients that are needed in an ICAP to meet the needs of the stakeholders. Through both database analysis and interviews, this thesis demonstrated that changes to the structure and processes of a standard care service delivery model may have affected important outcomes following intensive comprehensive aphasia treatment. These

outcomes were not only language and impairment based, but had a broader impact on people with aphasia and their family members, and clinicians.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

I acknowledge that an electronic copy of my thesis must be lodged with the University Library and, subject to the policy and procedures of The University of Queensland, the thesis be made available for research and study in accordance with the Copyright Act 1968 unless a period of embargo has been approved by the Dean of the Graduate School.

I acknowledge that copyright of all material contained in my thesis resides with the copyright holder(s) of that material. Where appropriate I have obtained copyright permission from the copyright holder to reproduce material in this thesis.

Publications during candidature

Published Manuscripts

1. Babbitt EM, Worrall LE, Cherney LR. (2013). Clinician perspectives of an Intensive comprehensive aphasia program. *Topics in Stroke Rehabilitation*, 20(5), 398-408.

2. Babbitt EM, Worrall L, Cherney LR. (2015). Structure, processes, and retrospective outcomes from an intensive comprehensive aphasia program. *American Journal of Speech-Language Pathology,* 24(4), S854-863.

3. Babbitt EM, Worrall L, Cherney LR. (2016). Who benefits from an intensive comprehensive aphasia program (ICAP)? *Topics in Language Disorders,* 36(2):168-184.

Published Conference Abstracts

1. Babbitt EM, Cherney LR, Worrall LE. Outcomes from an intensive comprehensive aphasia program (ICAP): A retrospective look. Poster presentation at the Clinical Aphasiology Conference, St. Simon's Island, GA (May, 2014).

2. Babbitt EM, Worrall LE, Cherney LR. Impact of type and severity of aphasia on outcomes in an intensive comprehensive aphasia program. Poster presentation at the Annual Convention of the American Speech-Language Hearing Association, Orlando, FL (November, 2014).

3. Babbitt EM, Worrall LE, Cherney LR. Factors contributing to improvements after participation in an intensive comprehensive aphasia program. Poster presentation at the Stroke Society of Australasia, Melbourne, AU (September, 2015).

4. Babbitt EM, Worrall LE, Cherney LR. Intensive comprehensive aphasia programs: The experience of persons with aphasia and their family members. Poster presentation at the Annual Convention of the American Speech-Language Hearing Association, Denver CO (November, 2015).

Invited Presentations

1. Babbitt, EM. Intensive Comprehensive Aphasia Programs. 3-hour platform presentation at the Illinois Speech and Hearing Association Annual Convention, Rosemont, IL. February 2014.

2. Babbitt, EM. Aphasia Interventions: Treatment Intensity and Partner Training. 4-hour platform presentation at the Iowa Conference on Communicative Disorders, Cedar Falls, IA. April 2016.

Publications included in this thesis

Incorporated as Chapter 2

Babbitt EM, Worrall L, Cherney LR. (2015). Structure, processes, and retrospective outcomes from an intensive comprehensive aphasia program. *American Journal of Speech-Language Pathology,* 24(4), S854-863.

Contributor	Statement of contribution
Author Edna M Babbitt	Completed the analysis (100%) Wrote the paper (70%)
Author Linda Worrall	Discussed, reviewed, and gave feedback regarding statistical analysis (50%) Wrote and edited paper (15%)
Author Leora Cherney	Discussed, reviewed, and gave feedback regarding statistical analysis (50%) Wrote and edited paper (15%)

Incorporated as Chapter 3

Babbitt EM, Worrall L, Cherney LR. (2016). Who benefits from an intensive comprehensive aphasia program (ICAP)? *Topics in Language Disorders,* 36(2):168-184.

Contributor	Statement of contribution
Author Edna M Babbitt	Completed the analysis (100%) Wrote the paper (70%)
Author Linda Worrall	Discussed, reviewed, and gave feedback regarding statistical analysis (50%) Wrote and edited paper (15%)
Author Leora Cherney	Discussed, reviewed, and gave feedback regarding statistical analysis (50%) Wrote and edited paper (15%)

Incorporated as Chapter 4

Babbitt EM, Worrall LE, Cherney LR. (2013). Clinician perspectives of an Intensive comprehensive aphasia program. *Topics in Stroke Rehabilitation*, 20(5), 398-408.

Contributor	Statement of contribution
Author Edna M Babbitt	Completed the analysis (100%) Wrote the paper (70%)
Author Linda Worrall	Reviewed the analysis and gave feedback (50%) Wrote and edited paper (15%)
Author Leora Cherney	Reviewed the analysis and gave feedback (50%) Wrote and edited paper (15%)

Contributions by others to the thesis

Dr Asaduzzaman Khan, statistician for The UQ School of Health & Rehabilitation Sciences, who provided statistical consultation regarding the database analysis and logistic regression.

Statement of parts of the thesis submitted to qualify for the award of another degree

None.

Acknowledgements

It's like a lifeboat.
Participant P10

Optimism is the faith that leads to achievement.
Nothing can be done without hope and confidence
Alone we can do so little; together we can do so much.
Helen Keller

Words, in my not-so-humble opinion,
are the most inexhaustible source of magic we have.
Albus Dumbledor

If you don't believe a dream can come true; it won't.
Sarina Levy

To use the words of one research participant, "It's like a life boat." I too have had a lifeboat full of people who have shared this voyage with me, one that has spanned the Pacific Ocean.

To Linda Worrall and Leora Cherney, my co-captains, thank you both for guiding my passage, teaching me how to navigate the seas of research and for being beacons of hope, that I would indeed make it to this point. I look forward to continued collaborations and partnerships. Leora, thank you for the conversation way back in 1999 which steered my career in a new direction. Linda, thank you for the conversation in 2011, which set the course for this journey.

I am deeply indebted to my husband, Larry, for your unwavering support from the day I brought up the idea of returning to school for my PhD. As my first mate, I am forever grateful that you have kept me on a steady course and were my anchor when the voyage got rough.

To our daughter, Sarina, thank you for being you, for your interest in learning about the brain, and for asking what was exciting in my day. Thank you for being my travel buddy when we visited Australia. Thank you, especially for reading road signs when Siri "lost her voice" and letting me know that we should **not** be driving on the highway headed to Sydney. And I can't forget to thank you for sorting and hole-punching all of my papers.

Thank you to my mom for being my mom and for instilling the love of learning in me and pushing me to keep learning. Your support, guidance, and love is what brought me to this point in my life.

Most of all, I am grateful to the participants with aphasia, their family members, and clinicians for sharing their words, stories, optimism, and hope with me.

In Memory of my Dad ~ E. Holt Babbitt III (1931-2015)
Who loved to ask questions
Who loved to write
Who knew the best coffee shops in town

Keywords

aphasia, rehabilitation, intensity, outcomes, language, participation, quantitative, qualitative

Australian and New Zealand Standard Research Classifications (ANZSRC)

ANZSRC code: 110321 Rehabilitation and Therapy, 80%

ANZSRC code: 170204 Linguistic Processes (incl. Speech Production and Comprehension), 20%

Fields of Research (FoR) Classification

FoR code: 1103, Clinical Sciences, 100%

Table of Contents

List of Figures & Tables

List of Abbreviations used in the thesis

ACOM = Aphasia Communication Outcome Measure

ACT = Anagram and Copy Treatment

Adv Degree = Advanced Degree

ALA = Assessment for Living with Aphasia

ANOVA = analysis of variance

Avg = Average

ASHA QCL = American Speech-Language Hearing Association Quality of Communication Life Scale

BNT = Boston Naming Test

CART = Copy and Recall Treatment

CAT = Comprehensive Aphasia Test

CCRSA = Communication Confidence Rating Scale for Aphasia

CETI = Communicative Effectiveness Index

D-LIFT = Distributed – Language Impairment and Functioning Treatment

EAAT = English version – Aachen Aphasia Test

F = female

FA14 = Fall 2014

FL= Fluent

HS Degree = High School Degree

ICAP = Intensive Comprehensive Aphasia Program

Inf Disease = Infectious Disease

LH = Left Hemisphere

LIFT = Language Impairment and Functioning Treatment

M = male

M = Mean

MPO = Months Post Onset

n = number of participants

NF = Non-fluent

ORLA = Oral Reading for Language in Aphasia

RET = Response Elaboration Training

RH = Right Hemisphere

RIC = Rehabilitation Institute of Chicago

SD = Standard Deviation

SFA = Semantic Feature Analysis

SP14 = Spring 2014

SVO = Subject Verb Object

TBI = Traumatic Brain Injury

TIR = Therapeutic Intensity Ratio

TUF = Treatment of Underlying Forms

VNeST = Verb Network Strengthening Treatment

WAB-R AQ = Western Aphasia Battery – Revised Aphasia Quotient

WAB-R CQ = Western Aphasia Battery – Revised Cognitive Quotient

WAB-R LQ = Western Aphasia Battery – Revised Language Quotient

1.0 Chapter One

1.1 Introduction

The purpose of this thesis is to describe outcomes from a specialized treatment model for people living with aphasia due to a stroke. This speech and language treatment model is called an Intensive Comprehensive Aphasia Program (ICAP). The outcomes for these types of programs are just beginning to be examined. This thesis provides a detailed quantitative and qualitative analysis of one such program located in a major metropolitan area in the United States. Previously, outcomes have only been analyzed through quantitative analysis. This thesis provides an in-depth examination of outcomes from one program through both quantitative and qualitative analyses. This chapter describes the framework of this thesis. It begins with describing the impact of aphasia after stroke followed by a summary of the state of speech-language treatment for individuals with aphasia in the United States. Then it discusses a model for measuring outcomes in health care environments which is based on evaluation of how the structure and processes within the environment can influence outcomes. Next, it defines intensive aphasia treatments and how the intensive comprehensive aphasia program (ICAP) examined in this thesis began. Finally, this chapter summarizes the research studies which form the body of this thesis.

The impact of aphasia after stroke

Stroke is the fifth most frequent cause of death in the US and the 17th most common cause of long-term disability.[1,2] Approximately 100,000 people with stroke are diagnosed with aphasia as the result of stroke each year.[3] Aphasia is a result of damage to the language areas of the brain. Subsequently, all modalities of language (i.e., speaking, listening, reading and writing) are impaired to varying degrees. Aphasia impacts a person's ability to function in typical daily activities such as interacting with family members and friends, returning to work, and accessing community activities.[4-7] Additionally, aphasia impacts psychosocial health as many persons with aphasia report increased depression, social isolation, and decreased quality of life.[6-13] Due do the confluence of these many factors, persons with aphasia and family members seek out treatment and support. ICAPs are one type of service that may address some of those issues.

Service delivery for aphasia treatment in the United States

The standard model of aphasia treatment in the US typically provides 2-3 hours of individual therapy per week for a limited number of weeks; the total number of hours is usually based on insurance limitations. The American Speech-Language-Hearing Association's National

Outcomes Measurement System (ASHA NOMS) identified that the number of sessions per week for stroke patients ranged from 1-3 sessions for 98% of patients on which data were reported.[14] More than half received an average of two sessions per week (59%). The length of each session range from 16-60 minutes, with 49% receiving 46-60 minutes per session. The length of time per session had not changed from multi-national survey results reported a decade earlier.[15] The average duration of outpatient treatment was reported to be 74 days or approximately 10.5 weeks. This equals approximately 20 hours of therapy provided over a period of 10 weeks.

In recent years, there has been an increase in the number of intensive comprehensive aphasia programs (ICAPs) which provide speech-language therapy to persons with aphasia (PWA).[16] These specialized programs offer additional and alternative therapy services as compared to those provided by the standard model of outpatient speech-language therapy. In stark contrast to standard care, ICAPs provide a minimum of one to two hours of individual therapy a day, plus group sessions and computer experiences, totaling as many as five to six hours of therapy per day for up to five weeks.[16] This equates to approximately 120 hours of therapy administered in half the amount of time reported in outpatient settings. The ASHA NOMS data set reported that the two primary reasons for discharge were treatment goals had been met and progress had plateaued. Although 75% of speech language pathologists did not recommend continued therapy, people with aphasia continue to seek additional therapy through ICAPs.

Other service delivery models address not only impairments but also include life experiences as part of the treatment, recovery, and health status for persons with disabilities. One of these models is the World Health Organization's International Classification of Functioning, Disability, and Health (WHO-ICF). The organization has included a person's functional abilities in the definition of health status.[17] These functional abilities may or may not be related to a specific disease condition. This broader view extends beyond typical health care outcomes gleaned from test results to include a person's activities and participation within society. Other research has found that persons with aphasia have goals that align with the ICF.[18-20] An ICAP is structured to provide comprehensive care that addresses functional goals related to activity and participation. [18-20]

Another model focuses specifically on aspects that contribute to living successfully with aphasia. Kagan and colleagues developed a model that is entitled: Living with aphasia:

Framework for Outcome Measurement (A-From).[21-23] This model highlights four areas of a person's life which can be affected by aphasia. These four domains are 1) participation in life situations, 2) communication and language environment, 3) personal identity, attitudes and feelings, and 4) Language and/or cognition. This model also may also be useful to describe an ICAP as it captures the comprehensiveness a variety of treatments, group settings, and family education and support. We suggest that the ICAP model addresses all four domains in the A-FROM and by examining more outcomes than just language and/or cognition, we can begin to identify how ICAPs may impact those areas.

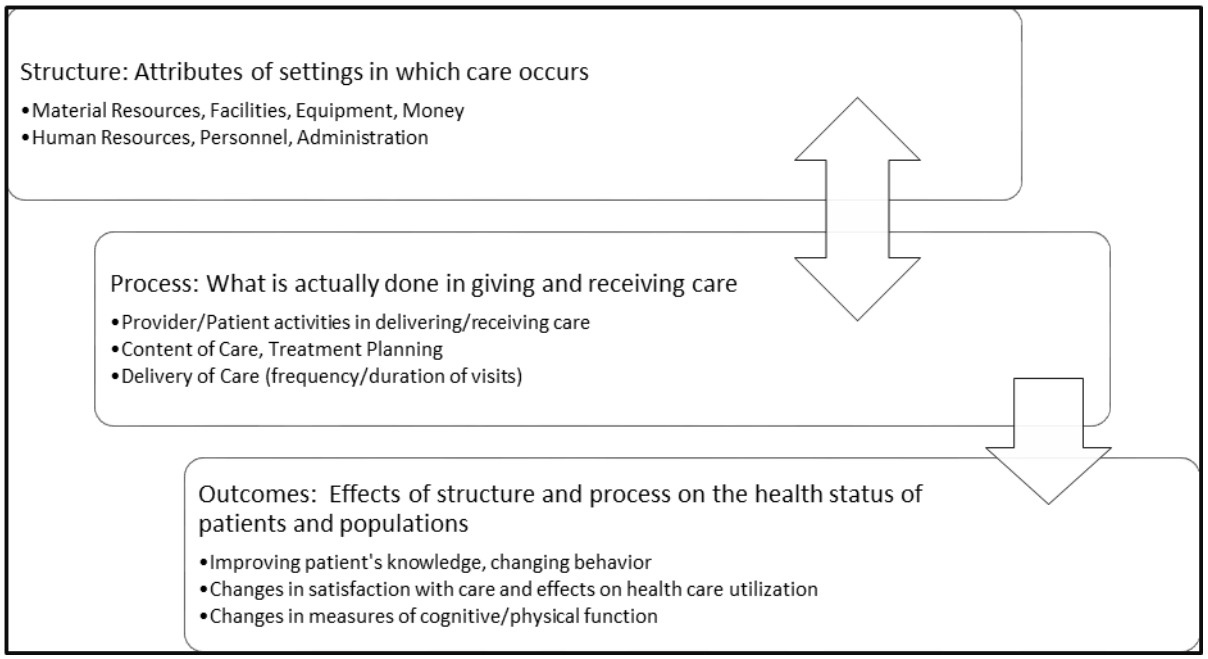
A model for evaluating outcomes in health care

The overarching aim of this thesis is to understand outcomes resulting from an intensive comprehensive aphasia program. An outcome is "something that happens as a result of an activity or process."[24] This implies that the implemented change can result in one of three different outcomes. A positive outcome means the implemented change had the desired effect, and negative change, or no change would occur if the activity or process did not function as expected. To determine whether the outcome was the expected result, that result must be measured against the pre-implemented state or against another measure. In health care settings, the outcomes most often measured are changes in patients' medical or functional status after a medical procedure or therapeutic intervention. Outcomes of a treatment can be examined in a variety of methods.

In the 1960s, Donabedian introduced a paradigm in which outcome was considered an integral component when assessing quality of health care.[25] Quality was described as "a reflection of values and goals current in the medical care system and in the larger society of which it is part." His paradigm demonstrated that changes to the structure and process within a health care setting led to changed outcomes. Therefore, modifications to the structure and process need to be described, understood, and integrated to be able to either define or replicate the outcomes. Structure includes but is not limited to: facilities, equipment, money, human resources, and administration.[26,27] Process refers to procedures of giving care including both treatment planning and delivery. Structure and process can be seen as the main ingredients which lead to outcomes of an organization or program (see Fig. 1.1). Implementing a change in structure or process may result in different outcomes; consequently, the structure and process should be described or measured to assess whether the implemented changes had the desired effect. Changes within the structure of an organization may include change in staffing numbers or change in the physical

environment of the setting.[28] Change could also be implemented in the process of care (i.e., the activities or content or how the care is delivered).[28]

Figure 1.1. Schemata of Donabedian's model of structure, process, and outcome



Since this initial model of structure, process and outcomes, there has been some debate and expansion of the model. For example, McAuliffe proposed the idea that the process is equally important as the outcome, contradicting Donabedian's paradigm.[29] He reported the arguments of others which stated that in order to evaluate the process, the reviewer must know initially which processes end with the best outcomes. Iezzoni and colleagues illustrated how the Donabedian model was essentially a linear model which lacked an important piece, client characteristics.[30] Iezzoni suggested that structure and client characteristics were both factors that influenced the process which then impacted the outcomes. However, client characteristics should be incorporated into the model with caution. Iezzoni also noted that differences in calculating patient risk of death (the outcome) based on severity (the patient characteristic) could account for significant variability predicting morbidity, illustrating how adding a patient characteristic into a model can impact predictive outcomes in unexpected ways.[31] In the nursing literature, Mitchell and associates proposed a more dynamic model in which the system (individual, organization, group) and client (individual, family, community) were the basis of the model and interacted with each other.[32] Interventions and outcomes were two additional factors, which had bi-directional impact on both the system and client. The authors noted that their "framework extends Donabedian's model by reflecting the dynamics among various components of systems of

care." While Donabedian's model initially provided a framework for describing and evaluating quality of health care, additional factors beyond structure and process impact outcomes.

Given the complexity of factors that contribute to outcomes, institutions have created centres focusing specifically on outcomes measurement. For example, the Rehabilitation Institute of Chicago's (RIC) Center for Rehabilitation Outcomes Research measures the long-term impact of rehabilitation on outcomes. Another facility, the Boston Rehabilitation Outcomes Center, investigates how to improve rehabilitation outcome measurement. Heinemann (2005) at RIC noted that routine use of clinical outcome measures allows programs to quantify the value of rehabilitation when clinical trial data are unavailable.[27] Historically, in the medical field, outcome measurement had been limited to objective assessments of change such as blood tests, MRI or other radiologic scans. In rehabilitation, outcomes are measured by physical, occupational, or speech and language therapy evaluations of impairment.[33] Clancy and Eisenberg also offer a broader view of outcomes based on health perceptions, functional measures, preference-based measures and patient satisfaction.[33] In summary, even though complex models of health care systems have been developed, the primary components and terminology of Donabedian's model can still be used to describe the components of health care. While structure and process remain important components, there is a need to measure and describe outcomes from those broader views. Health care is moving towards incorporating patient-reported outcomes and patient satisfaction as metrics to analyse outcomes.[33,34]

Intensity of aphasia treatment

While research has shown intensity is an important component in animal recovery models, how that knowledge translates to outcomes and human recovery from stroke and aphasia is not entirely known.[35] Research into intensive aphasia treatment alone has been equivocal in part because there is no standardized definition for what is considered to be "intensive." Over 10 years ago, Bhogal and colleagues discussed the notion that "more is better." They found that studies in which 8.8 hours of therapy per week for 11.2 weeks demonstrated significant treatment effects compared to studies in which therapy was provided only two hours a week for 22.9 weeks.[36,37] Almost a decade later, evidence is still equivocal about the efficacy of intensive aphasia therapy and the specific ingredients that allow for the best outcomes for individual persons with aphasia.[38-41] Cherney et al examined 11studies and found no clear differences in outcomes between intensive and non-intensive treatment

protocols.[41] The recommendations from their review were to examine the behavioural and neuroimaging results of intensive treatment independently and in combination with influencing factors. Factors that may impact recovery may not be readily measurable. These include: individual motivation, family support, pre-stroke language networks and connectivity, and clinician-related variables.[38] Additionally, Worrall et al found that determinants external to language function impacted a persons' ability to live well with aphasia.[42] They found in terms of self-report, higher participation was positively association with higher household income, gender (female), large social network, better physical functioning, and lower anxiety and depression. One determinant that was negatively associated with participation was higher levels of education. Future studies may be able to describe the impact of these factors and how these might be developed through targeted clinical practice.

In other studies of intensive treatment, examining dosage and time post-onset demonstrates that continued research is needed due to conflicting results. As Dignam and others found in a study comparing intensive and distributed treatment, participants in the distributed arm demonstrated equal gains on all measures but greater gains on the Boston Naming Test.[43] Looking at other randomized controlled studies, Allen et al discussed evidence that supports efficacy for a range of aphasia treatments, including an intensive treatment study, initiated six months or more after onset.[44] They found that treatment can be effective at a longer time post-onset, which contrasts with literature in biomedical stroke recovery that claims that recovery reaches a plateau at 6-12 months post-onset.[45] The most recent Cochrane review in 2016 indicated that intensive, higher dosage therapy or therapy over a longer time period may be beneficial.[46] However, reviewers also found that more intensive treatment may not be appropriate for all persons with aphasia as there was increased drop-out rate for more intensive treatment protocols.

Comprehensiveness of aphasia treatment

An ICAP is comprehensive because it incorporates treatment goals and procedures that potentially address all aspects of the WHO-ICF including impairment and activity/participation across educational, vocational, and recreational contexts. To accomplish this mandate, therapy is provided via different formats including individual and group treatment as well as computer treatment. The importance of addressing the activity/participation level has been influenced by concepts embedded within the life participation approach and the challenge of living successfully with aphasia.[47,48] Brown et al

found that persons with aphasia reported several themes related to living successfully with aphasia, including the importance of meaningful relationships and its sub-themes of "acceptance and understanding" and "social companionship."[49] An ICAP addresses these sub-themes by bringing together a cohort, a group of participants who begin and end the program together.[50] Northcott and colleagues found that reduced social networks following stroke and aphasia was associated with depression.[12] A literature review by Attard and others found that comments from participants in community aphasia groups could be grounded in psychological well-being domains.[51] Comments reflected that groups provided a means to form positive relations with others and to have a purpose in life. Other factors that were noted as outcomes to participating in groups were to have a sense of environmental mastery, autonomy, personal growth, and self-acceptance. Many people with aphasia say they have never met someone else with aphasia or have limited opportunities to interact with others. Another study found that two main benefits of taking part in aphasia groups were that groups provided 1) opportunities to meet others with aphasia and 2) opportunities to learn more about aphasia.[52]

As part of this ICAP, participants work together in small groups, have lunch together and meet up for dinners. Some socialize on the weekends. Brown et al identified another theme related to living successfully with aphasia, the "adoption of communication strategies for successful living."[49] In this ICAP, communication groups may be scheduled daily with a main goal to promote use of multimodal communication techniques to foster interactions between the participants. These strategies included using personal technological devices, writing key words, drawing, and gestures. Participation in this comprehensive program may help ameliorate the effects of reduced social networks and provide opportunities for interaction with others living with the same condition.

Providing family education in ICAPs is also part of the comprehensiveness of a program. Some research has described the importance of family involvement in the recovery process and identifies the needs of family members. A recent paper examined how speech-language pathologists included family education in their practice.[53] One barrier to providing family services was limited time on the part of the clinician possibly due to shorter hospital stays.[53] Howe and colleagues interviewed family members of persons with aphasia and found numerous themes that described what was important to them in caring for the person with aphasia to be: included in rehabilitation, provided with hope and positivity, given information and support, to communicate with their family member, and to look after their own

psychosocial health.[54] Ulatowska and associates analyzed narratives of persons with aphasia and found that the theme of family support was discussed often. The frequent mention of family support indicated that it was an important part of their stroke experience and stories about other memorable experiences. This demonstrated how meaningful support is for the person with aphasia. ICAPs may provide support for the family members that they do not get through standard care.

The Intensive Comprehensive Aphasia Program (ICAP) at the Rehabilitation Institute of Chicago

RIC's Intensive Comprehensive Aphasia Program (ICAP) started in 2008 in response to requests for an intensive program in the Chicago area. At that time, only a few programs were operating in the US and Canada, e.g., at the University of Michigan and Dalhousie University. A proposal for the operational expenses, staffing needs, facility requirements, and equipment needs was submitted to the administration. Approval for the program was granted and the physical location of the ICAP was set in an office building external to the main hospital due to space requirements. Recruitment of participants was initially completed through letters addressed to RIC physicians and other rehabilitation physicians in nearby regions. The first program in the fall of 2008 recruited 11 participants. Five participants were local and the rest were from around the US, Canada, and Israel. The second program occurred in July 2009 and four participants attended that program. After the low rate of recruitment for the summer program, it was decided to only operate in the spring and fall. Since that time, in 11 subsequent programs, almost all programs have had 10 participants and a wait list of potential participants. Recruitment for these programs was through word of mouth and advertising on the RIC website. The family or person with aphasia initiates contact by calling, emailing, or setting up an appointment with the director for information. Generally, participants have heard about the program from past participants, their speech-language pathologist or their medical doctor. The Director discusses suitability for the program, the structure of the day and the therapy that is provided. Participants are required to send in an application with a medical doctor's diagnosis of aphasia (and medical clearance to participate for the four weeks), most recent speech therapy notes, and intake information about current physical abilities, medications, work and education background, interests/hobbies and family or caregiver availability to support the person during the program. Approximately 30% of participants per cohort are returning participants. It should be noted that in this ICAP, participants pay out of pocket for the full cost of the program.

Therefore, participants in the program typically represent a selective group of people with aphasia regarding socioeconomic status.

The clinical staff who work in the program must have a minimum of three years of experience before working in the ICAP and attend a two-day pre-program workshop which includes all staff members, even those who have worked in the program previously. The aim of the training is to demonstrate evaluations and evidence-based treatments that new clinicians may not be familiar with and review for returning clinicians. There are five clinicians and each one is the primary clinician for two participants and responsible for individual treatments for those participants. This clinician is also responsible for discussing the evaluation results, participant's goals, and treatment plan during the first therapy session with the participant and family members. Goals are developed with input from the participant and family and focus on activities that the person would like to return to doing. They also facilitate group and partner sessions with all of the participants. One or two different clinicians facilitate the reading/writing group and the computer sessions. At most, two clinicians will be new to working in the ICAP for each cohort. An integral part of the structure of RIC's ICAP is daily staff meetings to plan group treatments, review patient progress, and discuss other issues concerning clinicians. Another integral part of the program, family education, is presented by the director and has dedicated time at the beginning and end of the program. As part of the program, families may be included in treatment sessions, educated on supported conversation techniques and stroke and aphasia, gain support from each other, and leave the participant for the first time since the stroke to do things for themselves. There were daily opportunities to seek information and education on how to best support their family member with aphasia.

As Donabedian defined, the process of treatment is comprised of many factors that occur during the delivery of a treatment. For this ICAP, the intensity of therapy is different as compared to a typical treatment session in an outpatient clinic. Clinicians focus on one specific evidence-based treatment for the duration of that hour of therapy. This is in contrast to more typical practice in the hospital's day rehabilitation or out-patient setting, where clinicians might focus on four different therapy tasks to ensure they address all of the patient's language deficits within the timeframe of the duration of the therapy. For example, clinicians might spend 15 minutes on verbal expression, 15 minutes on writing, 15 minutes on multimodal communication and 15 minutes educating the family on supportive conversation strategies. In this ICAP, the day is structured to provide a total of six hours of

therapy which includes two hours of individual treatment, one hour of treatment in pairs, one hour each of reading/writing and computer/technology treatment, and one hour of conversation group with no more than five participants. Due to there being separate hours focusing on reading and writing goals, computer/technology treatment, and conversation groups, the clinician has the ability to substantially increase the dose or the number of therapeutic events within the hour of individual treatment for one specific language goal. Evidence-based treatments are chosen for each participant. The initial evaluations provide information about the deficits, then a treatment plan is developed to address semantic, syntactic, and/or phonologic deficits in the context of each hour of therapy. Modifications and individualization are discussed in the daily meetings, with input from all clinicians. Some principles incorporated in the development of therapy activities and goals are consistent with principles used in standard care. These principles include integrating vocabulary related to biographical information (i.e., family members' names, frequently used sayings, vocabulary related to interests or hobbies), modifying treatments to accommodate severity levels, and creating treatment goals that are suggested by the participant (i.e., developing and practicing a speech).

The impetus for examining this ICAP and forming the body of work in this thesis was three-fold: 1) to add to the emerging research on measured quantitative outcomes from programs such as this, 2) to understand the perspectives of the primary stakeholders using qualitative methods, and 3) to identify how those perspectives may relate to outcomes found from the quantitative analysis. Hence, this thesis used retrospective data to quantitatively analyze pre-post evaluation measures and change in scores. Qualitative interviews were conducted specifically for these research studies, not retrospectively. Data was collected during two ICAP cohorts and then reviewed for themes that represented the experiences of the persons with aphasia and their family members. Clinicians from three different ICAP programs were interviewed over a time period of several months. The four studies in this thesis provide an investigation of the outcomes from one ICAP at the Rehabilitation Institute of Chicago to gain a greater understanding of what an intensive comprehensive program provides and possible reasons why participants take part.

1.2 Quantitative Studies: Research Questions

Research studies regarding outcomes from ICAP programs are emerging.[16,55-57] Previous research has found that overall, there are significant gains for persons with aphasia after taking part in an intensive program. One important finding from these studies was that not

all participants made significant gains across all of the areas measured, but most did make gains in at least one area. Chapters Two and Three examined results from the analyses of retrospective quantitative data from first-time participants in RIC's ICAP. This particular phase of analysis could be considered a precursor to a phase i/ii trial as it is describing the outcomes from the ICAP without the control of clinical trials.[58] This first step is to examine the effectiveness of an intensive comprehensive aphasia program by starting with the retrospective data. Only first time participants were included in the data analysis to eliminate the variable of participants receiving different amounts of therapy. Outcome data included demographic characteristics, language impairment measures and patient/family reported measures. These measures were administered as part of the routine clinical pre-post assessments.

1.2.1 Research questions

- Did first-time participants demonstrate improvements on the following types of outcome measures after taking part in an ICAP?
    - Impairment-based measures
    - Participation-based measures (participant and family member reported measures)
- Did the following variables have any impact on outcomes?
    - Severity of aphasia
    - Type of aphasia
    - Time post-onset
- Could profiles be developed which can predict clinical recovery patterns and better guide speech-language pathologists in making clinical treatment decisions and recommendations?

1.3 Qualitative Studies: Research Questions

Chapters Four and Five used a phenomenological approach to explore the experiences of different stakeholders regarding an intensive comprehensive aphasia program. The aims of the phenomenological approach are to explore "the meaning for several individuals of their *lived experiences* of a concept or a phenomenon (pg. 57)."[59,60] Themes were identified and analyzed using Ritchie and Spencer's framework analysis.[61,62] The main purpose was to explore stakeholder perspectives, similarities, and differences in experiences among participants, their family members, and staff clinicians. Ohman states (pg. 274), "As

rehabilitation outcomes are utterly dependent on patients' attitudes, thoughts and motivation regarding the rehabilitation process, and as the rehabilitation process in itself builds on social interaction, studies with a qualitative design can be useful tools in the development and improvement of rehabilitation."[63] General rehabilitation research has used qualitative methods to explore multiple stakeholder perspectives on participation in relation to living with a disability.[64] Stakeholder groups included persons with disabilities, caregivers, rehabilitation professionals, funders, and policy makers. For aphasia, multiple stakeholder perspectives have been explored through qualitative interviews related to living successfully with aphasia, goals for aphasia therapy, and ending speech therapy.[4,48,54,65-67] In one study, Dalemans and colleagues described a unique method in their qualitative study exploring social participation from the viewpoint of persons with aphasia and family members.[68] They asked participants to keep aphasia-friendly diaries regarding their activities over two weeks. Afterward, they conducted a semi-structured interview about thoughts and feelings related to participation activities. Another study used a phenomenological approach to analyse a case-study interview with a person with aphasia regarding the meaning of rehabilitation in his recovery process.[67] The chapters in this thesis added to the literature by exploring the perspectives of the main stakeholders: persons with aphasia and their families, and the clinicians who administered the treatment. Chapter Four presented thematic analysis of interviews from seven clinicians who represented three different programs and were asked to describe their experiences working in an ICAP. Chapter Five examined interviews from participants with aphasia and family members from one ICAP to develop common themes across their experiences.

1.3.1 Research questions

- What was the experience of clinicians who provided therapy in an ICAP?
- What was the experience of persons with aphasia and family members of their involvement in the ICAP?

1.4 SUMMARY

This chapter introduced the framework of this thesis. The residual deficits of stroke and aphasia have a significant impact. However, in the United States, there are limited resources devoted to speech-language treatment for aphasia. Persons with aphasia and family members seek additional treatment through intensive comprehensive aphasia programs. The chapter then discussed Donabedian's model of the structure, processes, and outcomes

in the context of one specific ICAP. Finally, this chapter summarizes the research studies which form the body of this thesis.

An ICAP is a specialized service delivery model based in principles of neuroplasticity and all components of the ICF. This model incorporates a variety of treatment approaches that target both impairment and participation communication activities. It is important to identify what benefits ICAPs bring to clients with aphasia.[69] The primary stakeholders, the participants, family, and clinicians, invest significant time and money to take part in ICAPs. Knowing the potential benefits of an ICAP may influence their decisions about whether to take part or not.

This thesis examines what changes were implemented to the structure and process of standard care to comprise the ICAP. It also examines the outcomes that were a result of those changes by analyzing behavioral change scores from pre- to post-treatment impairment and participation measures. Additionally, this thesis broadened the definition of outcomes from an ICAP and explored the personal experiences of stakeholders. Researchers have examined the components of an ICAP separately (intensity, comprehensiveness, and programs) but we do not know how these components in combination affect outcomes. By incorporating both qualitative and quantitative analysis, this thesis describes what it means to take part in this specialized treatment approach and demonstrates that intensive comprehensive aphasia programs may be a viable approach to provide enhanced treatment opportunities for persons with aphasia.

2.0 Chapter Two: Structure, Processes, and Retrospective Outcomes from an Intensive Comprehensive Aphasia Program

Chapter two aims to describe the characteristics of one Intensive Comprehensive Aphasia Program (ICAP). The characteristics were described in terms of Donabedian's Structure-Process-Outcomes model of health care quality assessment. This chapter also aimed to report results from a retrospective database analysis of first-time participants of the Rehabilitation Institute of Chicago's ICAP. The contents of this chapter were published as a manuscript, "Structure, process, and retrospective outcomes from an intensive comprehensive aphasia program" in the *American Journal of Speech-Language Pathology* (Babbitt, Worrall, & Cherney, 2015; Appendix A).[1]

2.1 Abstract

Purpose: This study describes the structure, processes, and outcomes of an intensive comprehensive aphasia program (ICAP). The aim was to identify treatment gains and determine if outcomes were significantly different between participants grouped according to severity and type of aphasia, and time post onset.

Method: Data from 74 first-time ICAP participants were analysed. Pre- and post-treatment scores on the Western Aphasia Battery – R and other impairment and participation measures were compared using paired t-tests. ANOVAs were used to compare outcomes related to aphasia severity (severe, moderate, and mild aphasia), aphasia type (fluent, non-fluent), and chronicity (0-6 months post-onset, 7-12 months post-onset and 12+ months post-onset).

Results: Participants made significant changes on all impairment and participation measures. Large effect sizes were noted for one participation and three impairment measures. Medium effect sizes were noted for one impairment and three participation measures. There was no significant difference between groups on any factor.

Conclusions: ICAPs can have a significant effect on the language impairment and participation of people with aphasia but further research is required to determine if the effect is comparable to other types of service delivery.

[1] The content included in Chapter Two is identical to the accepted manuscript, however, has been modified to match the formatting of this thesis document (including reference style). As such, the number, size and positioning of figures and tables is different to that of the published version.

2.2 INTRODUCTION

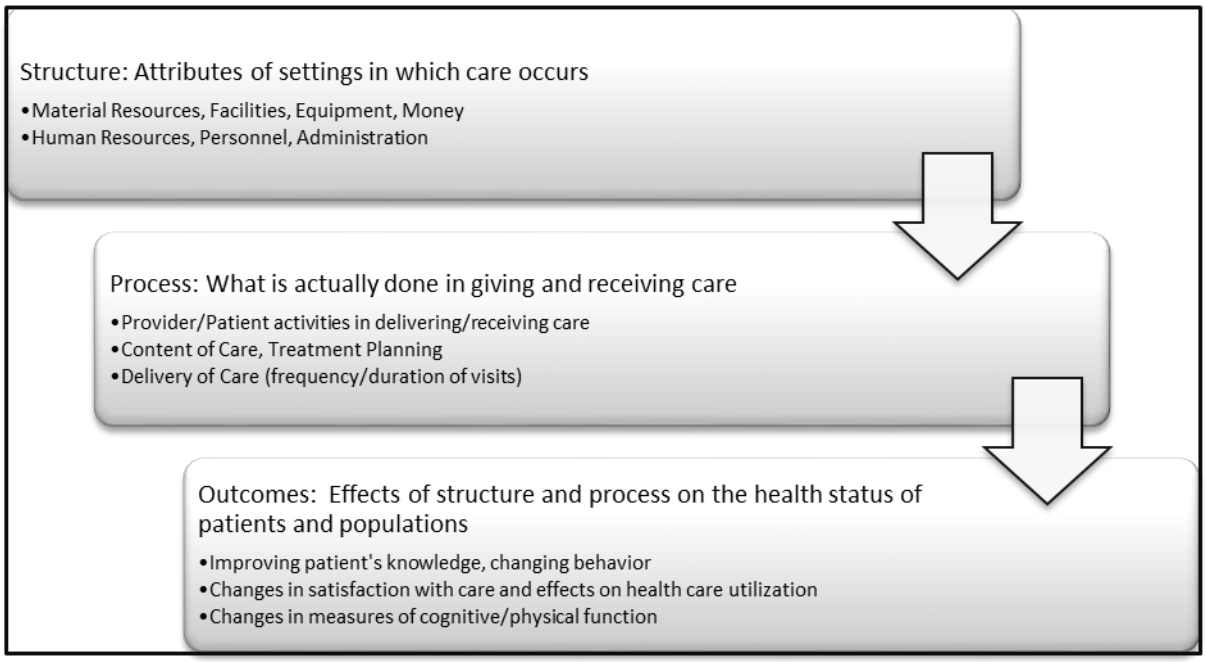
The number of aphasia programs that provide a unique combination of intensive and comprehensive speech-language therapy to persons with aphasia has increased.[50] According to a recent international survey, there are 12 such programs are in operation in the US and internationally that offer this type of therapy service as an alternative to the traditional model of outpatient speech-language therapy.[50] To be considered an Intensive Comprehensive Aphasia Program (ICAP), a program must target both impairment and activity/participation levels of language and communication treatment following the World Health Organization's International Classification of Functioning.[70] Additionally, a program must also provide at least three hours of therapy a day over at least two weeks to a cohort of participants that start and end the program at the same time.[50] The total number of reported therapy hours in ICAPs ranges from 48 to 150 hours. This is in stark contrast to typical outpatient treatment in the U.S. Many outpatient facilities provide two to three hours of therapy per week over approximately 12 weeks and termination of therapy usually occurs when insurance coverage limits are reached. Thus, intensity is one key factor which distinguishes the ICAP model from typical outpatient settings. Many of the principles of neuroplasticity that are associated with rehabilitation intensity and previously delineated by Kleim and Jones (2008) are incorporated into the ICAP philosophy including: repetition, salience, and transference.[35] The other key factor that defines an ICAP is the notion of comprehensive treatment which incorporates both language impairment treatment and activity/participation principles.[50] Activity/participation targets might include personal goal setting, interaction with others with aphasia, training in the use of multiple modalities for functional communication and patient/family education. Whether these two key components in combination translate into better outcomes is a fundamental question. Examining the outcomes from the ICAP model of aphasia service delivery is important to many stakeholders, including the participants and their families, many of whom pay out-of-pocket for the program, the clinicians, the organizations supporting the programs, and third-party payers, who may, in the future, reimburse for the program.

Research specifically on ICAPs that provide several hours of therapy a day over the course of a number of weeks with a cohort of participants has been minimal.[71] With the increasing number of programs being established, it is important to begin to define the interventions, responders and outcomes from this unique therapy model.[71] An emerging body of literature is beginning to assess outcomes from clinical ICAPs.[57,72-74] Hinckley and Craig (1998) retrospectively analysed the outcomes of an intensive comprehensive aphasia program in

which participants received 23 hours of therapy per week over six weeks.[72] They found significant improvements in participants' naming scores following intensive treatment as compared to no-treatment and less intensive treatment conditions (one to two hours or three to five hours per week for six weeks). In another retrospective analysis of outcome data that spanned more than 10 years, a majority of individuals in two different ICAPs made significant clinical change on impairment-based measures.[73] One of the programs reported that about half of the participants also made gains on participation-based measures. Other research-based intensive treatment programs have found that while individuals show different responses to treatment and some may show no response, improvements in at least one domain were noted for up to 96% of participants.[57,74]

On the surface, the differences between the ICAP model of therapy and traditional therapy are clearly identified as intensity and comprehensiveness. However, there are additional components of ICAPs which contribute to these differences and may impact outcomes. Donabedian (1966) described a model of health care that may provide a useful framework to illustrate how intensive therapy programs differ from traditional therapy. His model is based on principles of quality assurance and identifies how specific components of structure and process contribute to outcomes in medical and health care settings. Structure includes, but is not limited to: facilities, equipment, money, human resources, and administration.[26,27] Processes refer to procedures related to giving care including treatment planning and delivery. Structure and process are considered to be the main ingredients contributing to the outcomes of an organization or program (see Fig. 2.1).

Figure 2.1. Schemata of Donabedian's model of Structure, Process, and Outcome



Donabedian's premise is that implementing change in structure or process may result in different outcomes, and these need to be measured in order to assess whether the implementation had the desired effect. In the case of the ICAP, the structure and process of the typical clinical treatment model are greatly modified; therefore, there is an expectation that outcomes will be modified, too. Change can take place at the level of the structure of an organization, including modifying staffing numbers or changing the actual setting of the treatment.[28] Change can also be implemented in the process of care including the activities or content or how the care is delivered.[28] To illustrate, we describe the structure and process of one particular established ICAP that has been offering services for over six years. Later, we present outcome data from this same program.

The ICAP observed in this paper is situated in an urban rehabilitation center that offers inpatient and outpatient clinical services to persons with aphasia. However, the structure of the ICAP program varies from that of usual care. Because of the short-term nature of the ICAP, it does not have dedicated clinical staff or space. Additional necessary resources are needed including structured staff training, current computer technology equipment, support staff, and dedicated materials. All of these require time and money. The actual physical setting is separate from inpatient and outpatient clinical settings due to the large number of participants, family members and staff who must be accommodated in the ICAP. One benefit to separate space is that the ICAP treatment space is less hospital-like and more business-like. Considering many participants were in business or management careers prior to their

stroke, this setting may be more conducive to “getting back into life” versus a hospital setting which has a mark of illness. This concept of providing therapy outside of a medical setting was noted to be a positive factor by family members of another intensive treatment program.[56] While it may not lead to better outcomes, considering the physical attributes of the therapy setting and having an office-like milieu has the potential for higher participant satisfaction. Other logistical challenges that transient and off-site programs are faced with include: storage, set-up and break-down of computer equipment, office supplies, and evaluation and therapy materials. Staffing challenges occur as most therapy staff are recruited from other positions for the duration of the program and coverage for their usual positions is needed.

The processes involved in this ICAP are also different from typical clinical services. It was previously mentioned that the traditional model of outpatient therapy typically provides 2-3 hours of individual therapy per week for approximately 10 weeks for a total of 20-30 treatment hours versus an ICAP, in which participants can receive a range of 48 to 150 hours of treatment in a condensed time period up to six weeks.[50] This ICAP offers 30 hours of treatment a week for four weeks for a total of 120 hours. The program is offered twice a year accepting 10 participants in each program. Extensive evaluations are administered before the start of the program and at its conclusion. The assessment and progress reports are longer and more detailed as compared to the documentation in typical settings. The range of therapeutic approaches in the ICAP is much broader and comprehensive. During each day, participants in this ICAP receive two hours of individual therapy, and one hour each of reading/writing treatments, constraint-induced language therapy, computer-based treatments, and conversation or interactive group. There is a strong focus on goal setting with daily therapist meetings to ensure that each participant’s goals are integrated throughout every session by every clinician. All these factors contribute to a program meeting the definition of "comprehensive" which differs from typical outpatient treatment.

Clinicians who have worked in this and other ICAPs have identified other specific differences when treating in an ICAP as compared to the typical clinical setting.[75] An integral part of the process of organizing this ICAP includes training clinicians in evidence-based aphasia treatments. Clinicians noted that in typical clinical settings they have insufficient time to learn these techniques and read about the evidence that supports them. Daily staff meetings are held to plan group treatments, review patient progress, and discuss other issues of concern to clinicians. Clinicians identified these meetings as also as being different from typical

settings where there are time constraints. Another difference was the focus on conversation in group therapy in which participants were encouraged to use strategies for improved communication in participation-based activities (e.g., practice using iPad apps to respond to topics of interest, structured practice in communicative drawing, and practice with conversation starters). Clinicians also remarked that the opportunity for interaction between persons with aphasia was an important aspect of the program that they felt was extremely beneficial to the person with aphasia.[75] All of these different processes represent a therapy model which when implemented is vastly different from typical clinical treatments.

The Donabedian model emphasizes that changes in structure and process are important and directly relate to the quality of the outcomes. Therefore, a second aim of this paper is to describe the outcomes associated with this ICAP. Confounding factors are inherent in research focusing on any clinical programs. In most cases, the treating clinician performs the pre-post evaluations, thus clinician bias may be a confounding factor. Programs are typically expensive or have entry requirements about the level of independence required with activities of daily living. Participants are self-selected or selected a priori and are not randomized to treatment or control groups. Treatment fidelity may be breeched as clinicians use clinical judgment to modify treatments for a participant's specific deficits during treatment or adapted for deficits not addressed in the treatment research. Hula and colleagues (2013) outline what is lacking in research specifically regarding intensive comprehensive aphasia programs and the challenges faced in obtaining well controlled efficacy and effectiveness trials. A framework for how to evaluate complex interventions and how the framework can apply to research on ICAPs has been described by several authors.[58,71,76] Investigating outcomes using retrospective data falls into Phase 1 in this framework: defining the components of the intervention, and examining proof-of-concept, safety, and feasibility and acceptability. The second aim of this Phase I study is to describe the outcomes of 12 cohort programs (implemented twice a year over six years) from the ICAP previously described.

Identifying factors which may contribute to recovery from aphasia and potentially impact outcomes following participation in an ICAP is challenging but important, as factors unrelated to the intervention itself may contribute more or less to the recovery of each participant. Personal factors include age, education, gender, handedness, and other characteristics such as affect, depression, motivation, or family support. While some of these factors are difficult to measure or have not been routinely measured, some research has

shown that they may positively impact recovery.[77-79] Other research has found that such characteristics had minimal or mixed effect on recovery from aphasia.[80,81] Evidence is equivocal about the extent to which stroke-related or neurological characteristics such as time post onset, type of aphasia, and location and size of the lesion impact recovery.[81-85] However, it is likely that the interplay of multiple characteristics influences recovery from aphasia.[85] This article explores whether stroke/neurological characteristics of severity and type of aphasia, and time post onset impact improvements seen after participating in an intensive comprehensive aphasia program. The research questions are 1) Do first time participants in the ICAP demonstrate improvements on impairment and participation outcome measures? and 2) Do factors such as severity of aphasia, type of aphasia, or time post-onset of aphasia significantly influence outcomes?

2.3 METHODS

2.3.1 Participants

The study was approved by the Institutional Review Boards of Northwestern University and The University of Queensland. Eligibility to enter the program was based on a discussion between the director and the family regarding several factors: the person's endurance, level of independence with activities of daily living, potential for improvement, the severity of the person's aphasia (at both ends of the spectrum), recency of onset, and behavioural issues if the aphasia was due to a traumatic brain injury. Permission from the participant's physician was required for all participants to rule out medical issues which might interfere with participating in an intensive rehabilitation program. A caregiver was required to be present for some or all of the time if the participant was not independent in walking, eating, or toileting. Diagnosis of aphasia was confirmed from the most recent speech-language pathology reports provided by a speech-language pathologist. There were 84 first time participants across the 12 cohorts; however, only 74 participants completed both pre and post testing on the primary outcome measure, the Western Aphasia Battery – Revised Language Quotient (WAB-R LQ).[86] Ten participants were unable to complete pre and/or post testing due to factors such as the severity of aphasia, hospitalization prior to the end of the program, fatigue, or concomitant cognitive deficits. Table 2.1 shows the demographic information about these 74 participants. There were 49 participants with non-fluent aphasia and 25 with fluent aphasia based on WAB-R ratings. Of the 74 participants, 43 had an accompanying motor speech impairment of apraxia of speech (AOS) (n=40) and dysarthria (n=3). Most participants attended all 114 hours of treatment and six hours of evaluations except for occasional missed sessions due to outside appointments (occurring only 1-2

times for 1-2 participants). One participant became ill during the last week of the program and missed two days. None of the participants and clinicians had worked with each other previously.

Table 2.1. Demographics of 74 participants who completed the WAB-R LQ at pre-treatment and post-treatment

Sex	**Race/Ethnicity**	**Age**	**Native Language**	**Education**	**Handedness**
Male= 52 Female= 22	African Amer=2 Asian=1 Caucasian=71 Hispanic=3	Avg= 54.1 (SD=16.3) Range= 18-86	English = 70 Other = 4	Adv Degree= 30 4 yr. Degree= 18 Some College= 22 HS Degree= 4 9-11 grade= 0	Right= 68 Left= 6
Months Post-Onset	**Etiology**	**Aphasia Type**	**Motor Speech**	**WAB-R AQ score**	**WAB-R LQ score**
Avg= 15.5 (SD=14.7) Range= 3-87	LH stroke= 67 RH stroke=1 TBI= 3 Tumor= 1 Inf Disease= 2	Non-Fluent= 49 Fluent= 25	None=31 Apraxia of speech= 40 Dysarthria = 3	Avg= 51.3 (SD=21.8) Range= 7.2-91.4	Avg= 52.7 (SD=18.2) Range= 17.3-91

Avg = Average
SD = Standard Deviation
WAB-R LQ = Western Aphasia Battery – Revised Language Quotient
WAB-R AQ = Western Aphasia Battery – Revised Aphasia Quotient
Adv Degree = Advanced Degree
HS Degree = High School Degree
LH = Left Hemisphere
RH = Right Hemisphere
TBI = Traumatic Brain Injury
Inf Disease = Infectious Disease

2.3.2 Clinicians

Six treating clinicians provided treatment in each operational session of the ICAP. There were two consistent speech-language pathologists present at all 12 sessions and both had over 20 years of experience. Other clinicians who were temporarily reassigned to the ICAP from in-patient, out-patient and day rehabilitation settings had between two and fifteen years of experience with neurologically-based communication impairments. Most clinicians worked in the program two to three times and were familiar with the ICAP. During each operational session, five clinicians were responsible for evaluation and treatment of two participants each plus treating a CILT pair and facilitating a conversation group. One clinician facilitated the reading/writing groups and the computer lab.

2.3.3 Assessments

Impairment-based measures included the Aphasia, Language and Cognitive Quotients (AQ, LQ, and CQ) of the WAB-R and the Boston Naming Test (BNT).[86,87] Participation measures were obtained by self- and family-report and included the Communicative Effectiveness Index (CETI) which was completed separately by both the participant and family member, the American Speech-Language-Hearing Association Quality of Communicative Life (ASHA-QCL), and the Communication Confidence Rating Scale for Aphasia (CCRSA).[88-90] Diagnoses of motor speech disorder was initially obtained from prior speech-language pathologists' reports and confirmed by the treating clinician through formal and informal tasks including repetition, picture description, narrative speech, sound inventory assessment, and selected subtests of the Apraxia Battery for Adults.[91,92]

All tests were administered the first day of the program and during the last week of the program by the treating clinician. Administration and scoring procedures for all tests were reviewed with the experienced clinicians. Test scores and interpretations including ratings of fluency were discussed and any uncertainties were resolved by group consensus. In order to reduce clinician bias in testing, the program director who was familiar with every participant reviewed the test forms for accuracy in scoring. A second review of the test forms was conducted by the first author. Data entry of the test scores into a database was completed by the first author and 75% of entries were checked for accuracy by a research assistant with 98.5% inter-rater reliability.

2.3.4 Treatment

Each participant received the same number and types of treatment sessions daily which included two individual therapy sessions, and one session each of Constraint-Induced Language Therapy (CILT), reading/writing, computers and conversation group for a total of six hours of therapy per day. The therapy content and goals were individualized to each participant and carried through to all sessions throughout the day. Individual therapy sessions occurred once in the morning and once in the afternoon. Therapists were encouraged to spend an entire hour on one type of therapy to maximize intensive practice and number of repetitions associated with that treatment's focus and goals. The reading/writing and computer sessions were comprised of five participants each and the number of participants in the conversation groups ranged from 3-5 participants with 1-2 clinicians in each group. One hour a day was provided for lunch and participants and family members (if present) ate together. See Appendix G for a description of the types of therapies used during each hour.

Clinicians were trained in and administered a variety of evidence-based aphasia treatments which targeted individualized deficits. Examples of treatments used in this ICAP included Semantic Feature Analysis (SFA), Verb Network Strengthening Treatment (V-nest), Phonomotor Treatment, Constraint-Induced Language Therapy (CILT), Anagram and Copy Treatment (ACT)/Copy and Recall Treatment (CART), Treatment of Underlying Forms (TUF) and others.[93-98] Participants also used computer programs which have evidence to support their use with persons with aphasia.[99,100] Conversation group treatment followed a variety of discourse management strategies while incorporating individualized goals.[101] Although treatment focused primarily on language deficits, apraxia of speech was also addressed using articulatory-kinematic and rate-rhythm approaches.[92,102-104] Dysarthria was not treated in any participants due to the mild nature of the deficits.

Because this was a clinical program, clinicians were given latitude to implement treatments using their expertise and clinical judgment. However, several steps were taken to enhance treatment fidelity. Prior to the start of each program, clinicians were required to read articles on evidence-based treatments. Then, at a two-day training session, clinicians viewed videos of experienced clinicians implementing those treatments. Treatment sequences were discussed and practiced through role-play. Daily discussions during the program also provided opportunities for clinicians to ask questions about treatments and problem solve

with colleagues. For clinicians entering the program for the first time, the Program Director observed occasional treatment sessions and provided feedback on the implementation of the treatment procedures. About 10% of all treatment sessions were videotaped and reviewed by the Program Director. These strategies ensured that treatments were delivered according to design.

2.4 Results

To answer the first research question, do first time participants in an ICAP demonstrate improvements on outcome measures, the pre- and post-treatment scores across impairment and participation measures were examined. While 74 participants completed the subtests contributing to the WAB-R LQ, there were variations in the number of participants completing the other measures (see Tables 2.2 and 2.3). Reasons for the missing scores included: time limitations, fatigue, frustration and difficulty with tasks, and, for the CETI, unavailability of the same caregiver at the beginning and end of the program. In addition, the WAB-R CQ subtests were not required during the first three programs and scores were obtained from only 56 participants. Paired sample t-tests comparing pre- and post-treatment scores indicated significant improvement on all impairment and participation measures. Additionally, Cohen's d effect sizes for each measure were calculated on the pre-post treatment measures.[105] The ranges for effect sizes are the following: very large effect size (>=1.20 and <2.0; 2); large effect size (>=0.8 and <1.20); medium effect size (>=0.50 and <0.8.); and small effect size (small >=0.20 and <0.50). The three subscales of the WAB-R all demonstrated a very large effect size: (>=1.20 and <2.0); AQ (d=1.32), LQ (d=1.54), and CQ (d=1.7). The BNT showed a medium effect size (>=0.50 and <0.8.) (d=.79) (see Table 2.2). Of the participation measures, CETI responses from the care-givers demonstrated a large effect size (d=1.62) with pre to post-treatment change scores being similar to those obtained by Lomas et al. (1989). The other three participation measures demonstrated medium and small effect sizes (small >=0.20 and <0.50): CETI responses for the persons with Aphasia (d=0.73), CCRSA (d=0.47) and the ASHA QCL (d=0.41).

The analysis for the second research question about whether participants with different severities of aphasia, types of aphasia, or time post onset had significantly different outcomes was based on the WAB-R LQ change score. The ranges of severity and time post-onset categorical groups were determined after consultation with a statistician. Discussions included viewing distribution graphs of participant scores on the WAB-R and time post-onset to visualize any anomalies or outliers in the groupings. Categories were delineated based

on the number in each group to perform adequate statistical analysis. Since each participant in the program received reading and writing treatment in addition to treatment addressing verbal expression and auditory comprehension, we used the LQ change score as the primary outcome measure. The LQ incorporates scores from the reading and writing subtests along with the verbal expression and auditory comprehension subtests from the AQ.[106,107] To examine severity of aphasia, the scores were divided into three groups based on initial WAB-R LQ scores. A severe score ranged from 0-30 (n=6), a moderate score from 31-60 (n=43) and a mild score from 61-100 (n=25). The majority (58%) of the participants fell in the moderate range, with 8% and 34% of participants in the severe and mild groups, respectively. The WAB-R LQ difference score means and standard deviation were 7.6 (SD=3.2) for severe aphasia, 7.4 (SD=4.9) for moderate aphasia, and 5.4 (SD=3.5) for mild aphasia. An ANOVA demonstrated that there was no statistically significant difference between the severe, moderate and mild groups on the WAB-R LQ difference score ($F(2,72) = 1.77$, $p = 0.18$).

No effect of type of aphasia was observed on improvements following intensive aphasia therapy. The participants were divided into two groups with 49 non-fluent persons with aphasia and 25 fluent persons with aphasia. Non-fluent aphasia participants' mean pre-WAB-R LQ score was 48.7 (SD=17.9) and fluent participants' mean pre-WAB-R LQ score was 60.4 (SD=16.3). A two sample t-test with equal variances demonstrated that there was a significant difference in the mean pre-WAB-R LQ scores indicating that the fluent participants' pre-WAB-R LQ scores were significantly higher $t(72) = -2.73$, $p<.004$. This difference is most likely due to scoring conventions of the Spontaneous Speech subtest on the WAB-R AQ which factors into the total LQ score. Rating scores for fluency result in higher scores for persons with fluent aphasia. However, when examining the amount of change on the WAB-R LQ, the mean change score was 7.0 (SD=4.5) for non-fluent aphasia and 6.25 (SD=4.15) for fluent aphasia. A two sample t-test with equal variances demonstrated there was no significant difference in LQ change scores between the two types of aphasia $t(72) = 0.72$, $p=0.24$.

To evaluate whether time post-onset had an effect on recovery, the participants were divided into three categories based on the number of months from onset to the time of the evaluation. The categories were as follows: 0-6 months (n=15), 7-12 months (n=27), 13+ months (n=32). The means and standard deviation for the LQ change scores were 7.7 (SD=3.5) for 0-6 months, 7.5 (SD=5.7) for 7-12 months and 5.7 (SD=3.2) for 13+ months.

An ANOVA demonstrated that there was no statistically significant difference for the LQ difference score between the three categories of months post onset ($F(2,72) = 1.71$, $p = 0.19$).

Table 2.2. Change in Scores on Language Impairment Measures from pre-treatment to post-treatment

Language Measure	**WAB-R AQ /100**	**WAB-R LQ /100**	**WAB-R CQ /100**	**BNT /60**
Mean Pre (SD)	51.3 (21.8)	52.7 (18.2)	58.6 (17.4)	16.6 (19.0)
Mean Post (SD)	58.6 (21.3)	59.5 (17.9)	65.3 (16.6)	20.7 (20.5)
Difference	+7.2	+6.8	+6.7	+4.1
N=	74	74	56	71
	$t(73) = 11.4$	$t(73) = 13.3$	$t(55) = 12.7$	$t(70) = 6.6$
p value	<.001*	<.001*	<.001*	<.001*
Effect size	1.32=large	1.54 = large	1.7=large	.79=medium

Avg = Average

SD = Standard Deviation

WAB-R AQ = Western Aphasia Battery – Revised Aphasia Quotient

WAB-R LQ = Western Aphasia Battery – Revised Language Quotient

WAB-R CQ = Western Aphasia Battery – Revised Cognitive Quotient

BNT = Boston Naming Test

Table 2.3. Change in Scores on Participation Measures from pre-treatment to post-treatment

Participation Measure	CETI/100 Person with aphasia	CETI/100 Caregiver	ASHA QCL/80	CCRSA/40
Mean Pre (SD)	56.7 (16.5)	46.8 (15.7)	58.4 (10.7)	27.8 (5.9)
Mean Post (SD)	65.0 (17.5)	58.2 (16.2)	62.1 (11.4	30.1 (5.7)
Difference	+8.2	+11.4	+3.7	+2.3
N=	71	65	72	68
	t(70) = 6.2	*t*(64) = 13.1	*t*(71) = 3.5	*t*(67) = 3.9
P value	<.001*	<.001*	<.001*	<.001*
Effect size	.73=medium	1.62=large	.41=medium	.47=medium

SD = Standard Deviation

CETI = Communicative Effectiveness Index

ASHA QCL = American Speech-Language Hearing Association Quality of Communication Life Scale

CCRSA = Communication Confidence Rating Scale for Aphasia

2.5 Discussion

The first aim of this paper was to describe a specific ICAP in terms of its structure and processes. As Donabedian (1966) noted, it is important to identify the outcomes after implementing a change to the structure or processes within a clinical environment.[25] In this Phase I research, the description of the structure and process helps to define what additional components may be necessary for an ICAP program to obtain similar outcomes. We identified that several aspects of the structure of this ICAP were different when compared to the clinical out-patient treatment in the same facility: the space and location of the program, temporary personnel who staff the program, additional training for staff, and more materials (e.g., computers, iPads).[76] We saw other differences between this ICAP and the clinical out-patient treatment in the processes that occur during treatment delivery: the emphasis on evidence-based treatments and training staff in those treatments, more clinician time spent in treatment planning/discussions, different types of treatment (e.g., adding specific

sessions for groups and reading/writing treatment), and the overarching concept of providing intensity and comprehensiveness.

One particular challenge in the treatment literature has been the lack of a universal definition of what constitutes intensive therapy. One definition includes the dose, frequency and active ingredients in the delivery of the therapy.[108] Because there is a range of what researchers call intensive treatment, it is difficult to compare treatments and outcomes (Baker, 2012).[108] Currently, the maximum number of treatment hours reported for an ICAP is 150 hours (Rose et al., 2013).[50] Perhaps qualifiers are needed to help classify the "intensiveness" of intensive treatment. As Warren, Fey, and Yoder (2007) described, a formula for determining intensity would include the number of treatment items in a session (dose) X number of hours X number of days per week X number of weeks.[109] The spread of the treatment hours over the weeks should be considered. To quantify this spread of intensity of treatment, researchers may benefit from including an intensity ratio: the number of hours of treatment per week divided by the maximum potential hours of treatment per week. Since intensive programs are operating several hours a day over the course of a week, a standard 40-hour work week could be considered the maximum potential hours. This ratio could be termed the Therapeutic Intensity Ratio (TIR). For example, the ICAP under discussion provides treatment six hours a day for five days a week over four weeks. The total number of therapy hours provided (120 hours) divided by a maximum of 160 potential hours would yield a TIR for this ICAP of 75%. In comparison, a program that provides three hours a day for five days a week over two weeks would have a TIR of 37.5%, whereas a clinical treatment program providing two hours a week for 10 weeks would have a Therapeutic Intensity Ratio of 5%. This ratio may provide a starting point for ICAPs to begin to quantify how intensive the treatment is relative to changes in structure and process in Donabedian's model. Programs and any research regarding intensive treatments should begin to include the Therapeutic Intensity Ratio as a percent in their reports of outcomes along with the duration (number of weeks) and the dosage (the total number of hours) to give a true representation of the intensity of the treatment.

The second aim of the paper was to determine whether participants taking part in an intensive comprehensive aphasia program demonstrate improvement. Overall, the results from the analysis of 74 first time participants in this ICAP demonstrate intensive treatment has an effect. Significant improvements were seen in both language impairment measures and patient and family reported participation measures. A large effect size was seen in the

language impairment measures while moderate effect sizes were noted for three of the four the participation measures. Only the CETI responses from family members showed a large effect size. These results are comparable to other reported outcomes from intensive aphasia treatment programs. Hinckley and Craig (1998) found larger effect sizes on measures of naming during periods of intensive treatment (23 hours per week for six weeks) versus a reduced therapy schedule (3-5 hours per week for six weeks).[72] Rodriguez et al. (2013) also found significant change on a naming measure and participation measure, but interestingly, the effect size for the participation measure was larger than for the impairment measure.[57] The ICAP in the research by Rodriguez et al. (2013) had a strong participation focus which included an hour of functional therapy, challenge tasks (a project worked on throughout the program), and an emphasis on person-centered goal setting.

Additionally, we found there was no difference in change scores when exploring whether severity of aphasia, type of aphasia, or time post onset impacted the amount of change that was made. In comparing different severities of aphasia, the moderately severe group demonstrated the most change, but this was not significantly different from either the severe or mild groups and these two groups were not significantly different from each other. However, Persad et al. (2013) showed that persons with more severe aphasia as measured by the WAB-R AQ demonstrated most change on the AQ.[73] While initial severity of aphasia may not impact the amount of treatment-induced recovery, there was a significant difference between the non-fluent and fluent aphasia groups on their baseline WAB-R LQs. Other research with ICAPs has not differentiated baseline and change scores with regard to the type of aphasia.

Time post-onset also did not impact the amount of change a participant may make. No significant differences in response to treatment were observed for participants who were less than six months, 7-12 months or greater than a year post onset. With 80% of the participants in this study greater than six months post-onset and as long as seven years post onset, results also support the argument by Teasell et al. (2012) that providing therapy to persons with aphasia in the chronic stage can enable significant change.[110] Many participants considered to have chronic aphasia continued to make significant progress past the time period in which medical professionals report that plateaus occur. This continued improvement is important to note as most participants in ICAP programs are past the acute phase.[73] Results are consistent with those of Persad et al. (2013) who also found that time

post-onset did not predict which individuals demonstrated clinically significant improvement.[73]

2.5.1 Limitations

This paper reports an early phase investigation into the effectiveness of an intensive comprehensive aphasia program. The findings were not obtained via a randomized controlled trial, the treating clinician administered pre-post testing, and the participants were self-selected and self-pay. The selection bias suggests that this approach may not generalize to other persons with aphasia. Overall, participants in an ICAP are predominately younger white English-speaking males with higher levels of education.[73] While the characteristics of the participants in this study are different from the national picture of persons with aphasia, they are comparable to other ICAP program participants.[3,73,111] Other limitations to this study were that there was no follow-up was conducted to assess whether post-treatment changes were maintained, caregiver-specific outcomes were not assessed, and evaluation data were not collected on all participants as specific tests were not required during the first three programs. Because of the complexity in providing intensive comprehensive treatment, it is also difficult to identify the key ingredient in the structure or process of an ICAP which contributes most to the improvements we reported. It may be that a combination of factors such as the intensity, working together with a cohort, and participating in groups was important in facilitating these improvements.

Future research will examine similarities and differences in outcomes for repeat participants. Future research also needs to explore whether patient profiles can be developed to predict recovery patterns from an ICAP. Developing predictive equations may allow speech-language pathologists to make better treatment decisions and recommendations for ICAPS compared to other service delivery models.

2.5.2 Clinical implications

This research establishes that participants in this ICAP demonstrated improvement in language and participation measures. Future efficacy, cost effectiveness, and treatment comparison research using large scale randomised controlled trials is needed before statements can be made about the relative efficacy of ICAPs compared to other service delivery models. If the model proves to be cost effective, then it will be important to determine how to implement the program into usual care for people with aphasia. It may be possible to identify specific components which can be implemented by clinicians working in typical

treatment environments. One barrier to implementation of ICAPs into usual care identified by treating ICAP clinicians was that clinicians do not have the time in a work day to train themselves on an array of evidence-based treatments.[75] By making a change in the structure of an organization to provide more opportunities for training in evidence-based practices, some components of an ICAP could be implemented in typical treatment settings. If it is found that specific treatment techniques are important to recovery and improved outcomes, then clinician experience, training and treatment fidelity are important factors.

2.6 Conclusion

Outcomes from this program demonstrate that participants in an ICAP show significant improvement. For this ICAP, the largest effect sizes were seen in language impairment measures with only one participation measure showing a large effect size. The next phase of research would be to explore this treatment model and determine if positive change is a result of the treatment when compared to a no-treatment condition or a standard-treatment condition (Hula et al., 2013).[71] Future research may also use regression analysis to determine if factors such as severity of aphasia or type of aphasia can predict recovery.

3.0 Chapter Three: Who benefits from intensive comprehensive aphasia programs (ICAPs)?

Chapter Three aimed to examine whether there were factors that would predict who demonstrated significant improvements after taking part in an Intensive Comprehensive Aphasia Program (ICAP). The contents of this chapter were published as a manuscript, "Who benefits from an intensive comprehensive aphasia program (ICAP)?" *Topics in Language Disorders,* 36(2):168-184. Babbitt EM, Worrall L, Cherney LR. (2016). Appendix B).[2]

3.1 Abstract

Purpose: This article summarizes current outcomes from Intensive Comprehensive Aphasia Programs (ICAP) and examines data from one ICAP to identify those who responder and those who do not respond to treatment.

Methods: Participants were divided into two groups, responders and non-responders, based on ±5-point change score on the Western Aphasia Battery – Revised Aphasia Quotient. Independent sample t-tests and chi-square tests were performed to identify differences between groups on demographic (age and gender) and aphasia-related factors (months post-onset, type of aphasia, aphasia severity, naming, non-verbal cognition measure, and self-rating of communication confidence). Logistic regression determined if factors contributed to a treatment response.

Results: Significant differences were observed between the groups on age and months post-onset. Gender, type of aphasia, naming, non-verbal cognitive measure and communication confidence were not significantly different. Logistic regression indicated that age was the only predictive factor contributing to treatment response.

Conclusions: This study only identified age as a predictor of responders. Future research may need to examine a broader scope of variables that can impact recovery in aphasia.

[2] The content included in Chapter Two is identical to the accepted manuscript, however, has been modified to match the formatting of this thesis document (including reference style). As such, the number, size and positioning of figures and tables is different to that of the published version.

3.2 INTRODUCTION

In recent years, intensive comprehensive aphasia programs (ICAPs) have been increasing in number with a growing literature concurrently examining their outcomes.[43,50,55,57,72-74,112] To be considered an intensive program, an ICAP provides therapy ranging from 30 hours over two weeks up to 150 hours of therapy over four weeks for participants starting and ending at the same time.[50] To be considered comprehensive, a program will target impairment and activity/participation language skills, provide family education and use a variety of different treatments (e.g., individual, group, and computers). The number of hours of therapy and the overall intensity of therapy is greater than typically provided in outpatient settings. Outcomes from clinical ICAPs have been generally positive with many participants showing significant improvements across multiple language domains and in patient-reported outcomes; yet there are also participants who do not make changes.[55,57,73,74]

People with aphasia, family members, clinicians, supporting organizations, and insurance companies invest time and considerable resources into ICAPs. However, predicting who will benefit most from participation in an ICAP has not been studied. Recovery during rehabilitation is a complex process and many different factors contribute to recovery. Previous research in predicting recovery from aphasia has highlighted the heterogeneity of factors that leads to improvements.[113] These factors can be divided into neurological characteristics which include size and location of lesion, and type and severity of the aphasia.[114] Basso describes demographic characteristics as anagraphic which includes age, sex, and, handedness.[80] Some articles report that aphasia severity, lesion size, and lesion location are important for recovery.[81] Other have reported that type of stroke and aphasia, age, and education are factors which predict recovery.[115] Still others have noted that there is too much variability in initial severity, that lesion size and location might be a predictor, and that age, sex, handedness, and education do not seem to be important factors.[78] However, confounding pre-morbid neurological and health status characteristics, (i.e., learning disabilities, high blood pressure, diabetes, and depression) can impact deficits and recovery in ways that are not yet known.[77,114,116] Personal characteristics and environments such as motivation, personal beliefs, and family support may also impact recovery.[11,79,117] A challenge in interpreting prognostic studies is that there is sparse information regarding the type and amount of speech-language treatment participants received during long-term recovery.

It may be possible to examine factors that contribute to prognosis by looking at narrowing the focus to one type of therapy such as ICAPs. Table 3.1 summarizes the results of seven articles which report outcomes of Intensive Comprehensive Aphasia Programs (ICAPs). Considerable variation is apparent across the studies' methodology, type of treatment, intensity of treatment, and outcome measures which makes comparisons across studies difficult. Nevertheless, the outcomes indicate that participants in ICAPs do make progress, but progress is not uniform across the participants and not every participant makes progress in every area measured.

Table 3.1 Research to date on clinical and research intensive comprehensive aphasia programs

Clinical Intensive Comprehensive Aphasia Programs									
Authors	**Date**	**Title**	**Type of Program/ Research design**	**n=**	**Intensity**	**Components of Therapy**	**Outcome Measures**	**Significant Outcomes**	**Non-significant Outcomes**
Babbitt, Worrall, Cherney	2015	Structure, process, retrospective outcomes from an Intensive Comprehensive Aphasia Program	Clinical Single group Retrospective analysis Pre/Post	74	6 hours/day 5 days/week 4 weeks **120 hours total** **TIR= 75%**	Evidenced based Individualized Group Computer Family Education	Impairment: WAB AQ, LQ, CQ, BNT Participation: CCRSA ASHA QCL CETI (participant and family member)	Impairment: Significant change in all measures Large effect size = AQ, LQ, CQ Medium effect size = BNT Participation: Significant change in all measures Medium effect size = QCL, CCRSA, CETI (participant) Large effect size = CETI (family member)	Impairment: ANOVA showed no significant differences in LQ change scores on: months post-onset, severity of aphasia, type of aphasia
Winans-Mitrik, Hula, Dickey, Schumacher, Swoyer, Doyle	2014	Description of an intensive residential aphasia treatment program: Rationale, clinical processes, and outcomes	Clinical Single group Retrospective analysis Baseline/Pre/Post	73	5 hours/day 5 days/week 4 weeks **100 hours total** **TIR=62.5%**	Evidenced based Individualized Group	Impairment: CAT Discourse: Story Retell Procedure Participation: ACOM (participant and family member)	Significant group change from baseline to pre-treatment on all measures Greater magnitude of change and rate of change on all measures from pre- to post- treatment as compared to baseline to pre-treatment	

Persad, Wozniak	2013	Retrospective analysis of outcomes from two intensive comprehensive aphasia programs	Clinical Single group Retrospective analysis Pre/Post	54	4.5 hours/day 5 days/week 6 weeks **138 hours total** **TIR=57.5%**	Research-based Individualized Social & Recreational activities Caregiver participation	Analysis of Responders (>=5 pt. change on WAB AQ) compared to Non-responders (<5 pt. change on WAB AQ)	Significant difference = Responders have more severe initial AQ Significant correlation = Lower initial AQ score correlates with greater AQ change score	ANOVA showed no significant differences of Responder versus Non-responder in AQ change scores for: age, months post-onset, and gender No correlations for age, months post-onset and AQ change scores
Persad, Wozniak	2013	Retrospective analysis of outcomes from two intensive comprehensive aphasia programs	Clinical Single group Retrospective analysis Pre/Post	70	5 hours/day 5 days/week 4.5 weeks **112.5 hours total** **TIR=62.5%**	Evidence-based Individualized Computer Social/Community /leisure activity	Impairment: WAB AQ Participation: CETI CADL-2	Impairment: Significant change for 1/3 of participants on WAB AQ Participation: Significant change for ~1/2 of participants on CETI and CADL-2 Significant correlation between Initial AQ score and CADL change score Factors: Significant correlation for age and time post-onset (older and longer time post onset may	No correlation for AQ change scores, CADL and CETI

								have < AQ change scores) Significant correlation for age and gender (male participants younger than female)	
Hinckley Craig	1998 Study 1	Influence of rate of treatment on the naming abilities of adults with aphasia	Clinical Single group Retrospective analysis Pre/post/follow up ABA: 6 weeks- Intensive 6-8 weeks- No treatment 6 weeks- Intensive	15	4.5 hours/day 5 days/week 6 weeks **135 hours total** **TIR=56%** versus No therapy	Individualized treatment Small group Computers	Impairment: BNT Discourse: Cookie Theft Picture content units	Significant change during 1st Intensive on BNT and Discourse content units Significant change during 2nd Intensive on BNT and Discourse content units	No significant change during no treatment phase
Hinckley Craig	1998 Study 2	Influence of rate of treatment on the naming abilities of adults with aphasia	Clinical Single group Retrospective analysis Pre/post/follow up ABA: 6 weeks- Intensive 6 weeks- <3 hours/week SLT 6 weeks- Intensive	15	4.5 hours/day 5 days/week 6 weeks **135 hours total** **TIR=56%** versus <3 hours/week 6 weeks **<18 hours total** **TIR=<7.5%**	Individualized treatment Small group Computers	Impairment: BNT Discourse: Cookie Theft Picture content units	Significant change during 1st Intensive on BNT and Discourse content units Significant change during 2nd Intensive on BNT and Discourse content units	No significant change during non-intensive treatment phase
Hinckley Craig	1998 Study 3	Influence of rate of treatment on the naming abilities of adults with aphasia	Clinical Single group Retrospective analysis Pre/post/follow up ABA:	15	4.5 hours/day 5 days/week 6 weeks **135 hours total** **TIR=56%** versus	Individualized treatment Small group Computers	Impairment: BNT Discourse: Cookie Theft Picture content units	Significant change during 1st Intensive on BNT Significant change during 2nd Intensive on BNT and	No significant change during 1st Intensive on Discourse content units

	6 weeks- Intensive 6 weeks- 3-5 hours/week SLT 6 weeks- Intensive	3-5 (avg. 4) hours/ week 6 weeks **18-30 hours total** **TIR=7.5-12.5%**		Discourse content units	No significant change during non-intensive treatment phase

Research Intensive Comprehensive Aphasia Programs									
Authors	**Date**	**Title**	**Type of Program/ Research design**	**n=**	**Intensity**	**Components of Therapy**	**Outcome Measures**	**Significant Outcomes**	**Non-significant Outcomes**
Dignam, Rodriguez Copland	2015	Evidence for intensive aphasia therapy	Research Phase II non-randomized Parallel-group Pre/post/follow up	LIFT: 16 D-LIFT: 16	LIFT: 3-4 hours/day 16 hours/week 3 weeks **48 hours total** **TIR=40%** versus Distributed LIFT: 1-2 hours/day 3-4 days/week 6 hours/week 8 weeks **48 hours total** **TIR=15%**	Naming treatment Computers Group education	Impairment: BNT Participation: CETI (family) CCRSA ALA	Impairment: Significant changes in LIFT and D-LIFT at post-treatment and follow up D-LIFT showed significantly greater changes than LIFT at both post-treatment and follow up Participation: CETI and CCRSA were significantly higher for both groups post-therapy ALA was significantly higher for both groups post-treatment and follow up	Participation: No significant differences between LIFT and D-LIFT on CETI, CCRSA, and ALA at post-treatment and follow up
Rodriguez Worrall, Brown, Grohn, McKinnon, Pearson, Van Hees, Roxbury, Cornwell,	2013	Aphasia LIFT: Exploratory investigation of an intensive comprehensive aphasia program	Research Pre/post/follow up	LIFT1: 4 LIFT2: 7	LIFT1: 4 hours/day 5 days/week 2 weeks **40 hours total** **TIR=50%** LIFT2: 5 hours/day	Goal setting Family education Individual therapy Evidence-based treatments Group Challenge task Computer (LIFT2)	Impairment: CAT – Naming subtest BNT Discourse: Procedural and narrative production-	Impairment: Significant but small change on BNT Participation: Significant change on CETI post-	Impairment: No Significant change: CAT Naming No Significant change: Discourse Participation:

MacDonald Angwin, Cardell, Davidson, Copland					5 days/week 4 weeks **100 hours total** **TIR=62.5%**		content information units Participation: CETI (family) ASHA QCL ALA	treatment and further increases at follow up Significant change on ALA post-therapy	QCL approached significance on follow up
Code, Torney, Gildea-Howardine, Willmes	2010	Outcome of a one-month treatment intensive for chronic aphasia: Variable individual responses	Research Small group Single Subject 3 Baselines/post/ follow up	7	1 month – daily treatment (no other description, based on Mackenzie [56])	Individualized (no description) Group (no description, except AOS group) Counseling offered to participant Family counseling & education	Impairment: EAAT Participation: CETI	Impairment: Significant change pre- to post-treatment and post-treatment to follow up Participation: Significant changes on CETI for 3 participants and maintained at follow up	Participation: No Significant change on CETI for 3 participants (no scores for 1 participant)

Key: n = number of participants; TIR = Therapeutic Intensity Ratio; WAB-R AQ, LQ, CQ = Western Aphasia Battery-Revised Aphasia Quotient, Language Quotient, Cognitive Quotient; CCRSA = Communication Confidence Rating Scale for Aphasia; ASHA QCL = American Speech-Language-Hearing Association Quality of Communicative Life; CETI = Communicative Effectiveness Index; BNT = Boston Naming Test; ANOVA = analysis of varience; CAT = Comprehensive Aphasia Test; ACOM = Aphasia Communication Outcome Measure; LIFT = Language Impairment and Functioning Treatment; D-LIFT = Distributed – Language Impairment and Functioning Treatment; ALA = Assessment for Living with Aphasia; EAAT = English version – Aachen Aphasia Test

In terms of the types of therapy provided in the programs, four report on clinical treatment programs and three were research studies. All but one reported using evidence-based treatments and another one did not describe the therapy beyond mentioning it was individualized.[55,72] All reported a social or group component. Four of the studies mentioned a family component, with family either participating in therapy or receiving education.

Another difference between the ICAP studies that makes cross-study comparisons difficult is the intensity of treatment provided. The ICAPs reported delivering 16 to 30 hours of therapy per week, demonstrating there is a range of what is deemed intensive. One approach to describing intensity is to not only report the number of hours of therapy provided, but to include a measure of how intensive the therapy was provided. Using the Therapeutic Intensity Ratio (TIR) described by Babbitt, Worrall, and Cherney, the "intensiveness" of the treatments can be compared.[112] The TIR is a ratio of how many hours of therapy are delivered per week divided by the total potential hours of therapy that could be delivered, using a 40-hour work week as a maximum number of hours. Based on the reported number of hours of therapy per week, the Therapeutic Intensity Ratio (TIR) for these studies ranges from 40% to 75%. In contrast, the TIR for distributed treatment in the studies which compared intensive to distributed treatments ranged from 7.5 to 15% TIR.[43,72] It is not yet clear what the optimum treatment intensity should be.[43] Reporting on the "intensiveness" of a treatment program will allow for better interpretation of outcomes across studies. With additional research studies, it may be possible to define and distinguish between minimal, moderate or maximal intensity treatment protocols. As Baker noted, there is a lack of consensus regarding the definition of intensive treatment.[108]

An examination of the outcome measures used across ICAP studies revealed that there was inconsistency regarding what measures were included. The clinical programs reported using the Western Aphasia Battery-R (WAB-R),[86] Boston Naming Test (BNT),[87] Communicative Activities of Daily Living-2 (CADL-2),[118] the Comprehensive Aphasia Test (CAT),[119] and discourse for impairment-based measures. Research ICAPs used the CAT, the Aachen Aphasia test (AAT),[120] BNT, and discourse. There was considerable variability in which discourse measures were used and the tasks and analyses are listed in Table 3.1 for the studies that analyzed discourse. For participation measures, the clinical programs used the Communication Confidence Rating Scale for Aphasia (CCRSA),[83] American Speech-Language-Hearing Association – Quality of Communicative Life (ASHA QCL),[90,121] the Communicative Effectiveness Index (CETI) for care-givers and for persons with aphasia,[89]

and the Aphasia Communication Outcome Measure (ACOM) for care-givers and persons with aphasia. The research ICAPs used CCRSA, QCL, CETI for care-givers, and the Assessment for Living with Aphasia (ALA).[23] The variety of measures highlights the lack of consensus on which assessments should be administered to measure impairment and participation.

Most ICAP studies reported positive and significant changes from pre- to post-treatment on the selected outcome measures. It is difficult to make broad conclusions about the results because of the small number of studies, differences between research and clinical programs, differences in the number of participants, and the variety of outcome measures. Babbitt and colleagues reported significant differences on all impairment and participation measures from pre- to post-treatment.[112] Effect sizes were large for the WAB Aphasia Quotient (AQ), Language Quotient (LQ), and Cognitive Quotient (CQ) and moderate for the BNT. Family-reported effect size was large on the CETI and moderate for participant-reported CETI, ASHA QCL, and CCRSA. Winans-Mitrik and others described improvements from baseline to the start of the program;, however, participants were receiving on-going treatment during that interim.[74] The authors found that during the intensive program the magnitude of change from pre- to post-treatment was significantly greater than during the baseline phase. Rodriguez and colleagues noted that on the BNT and participation measures there were significant differences and two participation measures showed significant differences at follow up.[57] Dignam et al compared an intensive treatment to a distributed treatment and found that both groups improved significantly from pre- to post-treatment on the BNT and the distributed group demonstrated significantly greater improvement at post-treatment and follow up.[43] The participation measures showed significant differences at post-treatment and follow up for both groups and no significant differences between the groups at either time point. Hinckley and Craig also compared intensive treatment versus little or no treatment and reported significant change from pre- to post-treatment for the intensive treatment and no change during non-intensive and no-treatment phases.[72]

Only one study has explored what characteristics may contribute to improvements of greater than or equal to five points on the WAB-AQ score. Persad and colleagues examined two different programs. In one ICAP, there was no significant difference between responders (scored greater than or equal to five points)(81%) and non-responders (19%) in terms of age, time post-onset, and gender.[73] There was a significant difference in initial severity on

the WAB AQ between the groups. The responders were initially more severe; however, three of the non-responder group were at or close to ceiling and did not make significant changes. In the other ICAP program, approximately half of the participants demonstrated significant improvements in participation measures and approximately two-thirds in impairment measures. Only three (4%) participants did not show gains on any measure. There was no difference between the groups related to age, gender, time post-onset and initial WAB AQ. The authors did find a relationship with WAB AQ change scores that suggested older participants attended at a later time post-onset and men sought treatment at a younger age than women.

Building on the findings of Persad et al, the aim of this study was to further explore participant factors that are associated with benefit from an ICAP.[73] We have previously reported on retrospective outcomes from 74 participants in a clinical ICAP and found that there were significant gains from pre- to post treatment on all impairment and participation measures.[112] This is a secondary analysis of the data set which includes an additional nine first-time participants (n=83) from a consecutive cohort. This analysis was undertaken to examine whether any independent variables contributed to response to treatment (dependent variable) following participation in an ICAP.

3.3 METHODS

3.3.1 Participants

Data from 83 first-time participants were included in the data analysis. The month-long clinical ICAP was offered twice a year from 2008 to 2014 for a total of 12 programs. Pre- and post-evaluations took place on the first day of the program and during the last week of the program. Retrospective analysis of the clinical data was approved by Institutional Review Boards of Northwestern University and the University of Queensland. Seventy percent of the participants were male and 94% were right-handed. The average age was 54.6 years (SD=16.1, range 18-86) and average time post onset was 15.1 months (SD=14.1, range 3-87). Reported education level showed that 42% had advanced degrees, 52% had some college or a four-year degree, and 6% had completed high school or at least 9-11th grade. Ninety-six percent of the participants were Caucasian and 4% were African American or Asian. The average pre-treatment WAB-R AQ score was 49.2 (SD=22.4, range 7-91.4). Sixty-nine percent of participants were diagnosed with non-fluent aphasia and 31% with fluent aphasia. Sixty percent had a diagnosis of motor speech impairment including apraxia of speech (55%), dysarthria (4%) or both (1%).

3.3.2 Assessments and treatment

Participants in this ICAP were assessed with impairment and self-reported outcome measures. Impairment measures included the Western Aphasia Battery-Revised (WAB-R), including the aphasia, language, and cognitive quotients (AQ, LQ, CQ) and the Boston Naming Test. Patient-reported outcome measures assessed participation with the ASHA QCL, the CCRSA, and the CETI (completed by both participant and a family member). The treatment in this ICAP was provided for six hours a day, five days a week for four weeks for a total of 120 hours (75% TIR) to a cohort of 10 participants in two cohorts per year. For detailed description of the assessments, treatment, and program structure refer to Babbitt, Worrall, Cherney [112]

3.3.3 Data analysis

The 83 first-time participants were divided into two groups: responders and non-responders. Responders were defined as participants who achieved five points or greater improvement on the WAB AQ from pre- to post-treatment. Non-responders were those participants who did not achieve a five-point change. A five-point change has been used as a benchmark for change in previous studies hence this criterion was selected as an indicator of benefit from the program.[73,122] Independent samples t-tests and chi-square were performed to determine if there were significant differences between the two groups. A logistical regression was then used to identify the factors which may contribute to a treatment response to the ICAP. The independent variables included age, months-post-onset, type of aphasia, aphasia severity, naming, non-verbal cognition measure, and self-rating of communication confidence**.**

3.4 RESULTS

Of the 83 first time participants, there were 57 responders (69%) compared to 26 non-responders (31%). Independent samples t-tests showed that responders were significantly younger with longer time post onset than the non-responders ($t(81) = 2.0$, $p<.02$ and $t(81) = -1.8$, $p<.04$.)**.** Based on Pearson's chi-square test, gender and type of aphasia were not significantly different between the groups. There were no significant differences between responders and non-responders on the severity of aphasia measured by the WAB-R AQ score, the BNT, the Ravens Progressive Matrixes (non-verbal cognition), or communicative confidence (CCRSA). As expected, independent samples t-test demonstrated that the two groups were significantly different on the mean change scores of the WAB AQ ($t(81) = 9.0$, $p<.000$). See Tables 3.2 and 3.3 for results of independent sample t-tests and chi-square.

Table 3.2. Comparison of Responders' and Non-Responders' Demographic Characteristics

	Age	Months Post Onset	Gender		Type of Aphasia	
Mean Resp (SD)	52.2 (16.5)	16.9 (16.3)	F/M	19/38	NF/FL	41/16
Mean NResp (SD)	59.8 (14.1)	11.0 (5.7)	F/M	6/20	NF/FL	16/10
Difference	-7.6	+5.8				
N=	83	83	83		83	
	$t(81) = 2.0$	$t(81) = -1.8$				
			$X^2 = .89$		$X^2 = .90$	
p value	<0.02*	<0.04*	<0.35		<0.34	

∗ Indicates significant difference

a) Resp= Responder, b) NResp= Non-Responder, c) SD= Standard Deviation, d) F= female, e) M= male, f) NF= Non-fluent, g) FL= Fluent

Table 3.3. Comparison of Responders and Non-Responders on Initial Impairment and Participation Measures

	WAB-R AQ Difference Score	WAB-R AQ /100	BNT /60	Ravens /37	CCRSA /40
Mean Resp (SD)	10.1 (4.5)	47.17 (18.9)	14.7 (18.2)	30.4 (4.7)	27.0 (6.5)
Mean NResp (SD)	1.3 (3.0)	53.61 (28.51)	19.3 (20.8)	30.2 (4.7)	28.5 (5.3)
Difference	+8.8	-6.4	-4.6	-0.11	-1.5
N=	83	83	78	60	83
	$t(81) = 9.0$	$t(81) = 1.2$	$t(76) = .97$	$t(58) = -0.08$	$t(81) = 1.0$
p value	<.000*	<0.11	<0.17	<0.5	<0.16

∗ Indicates significant difference

a) Resp= Responder, b) NResp= Non-Responder, c) SD = Standard Deviation, d) WAB-R AQ = Western Aphasia Battery – Revised Aphasia Quotient, e) BNT = Boston Naming Test, f) CCRSA = Communication Confidence Rating Scale for Aphasia

The logistic regression included factors of age, months post-onset, type of aphasia, initial severity of aphasia and change scores on the BNT, Ravens Progressive Matrixes, and the CCRSA to identify whether any factor had an impact on response to treatment (i.e., WAB

AQ change score). The model was not statistically significant (X^2 (7) = 11.13, p <.113) and only age was a significant factor (p< .027). See Table 3.4.

Table 3.4. Logistic regression results of factors that contribute to response to treatment

AQ_Bin	*Coef.*	*Std. Err.*	*z*	*P > | z |*	*[95% Conf. Interval]*	
AgeEval1	-.0547804	.0247635	-2.21	0.027	-.1033159	-.0062448
MPOEval1	.0646623	.045863	1.41	0.159	-.0252276	.1545521
TypeAph	.724964	.9213061	0.79	0.431	-1.080763	2.530691
AQ1_100	-.0367806	.0321172	-1.15	0.252	-.0997291	.0261679
BNT1_60	.0453133	.0332797	1.36	0.173	-.0199137	.1105402
Rav1_37	-.0637839	.0788451	-0.81	0.419	-.2183174	.0907496
CCRSA1_40	-.0243009	.0576266	-0.42	0.673	-.137247	.0886453
_cons	6.003454	3.664301	1.64	0.101	-1.178443	13.18535

a) AQ_Bin = binary assignment to responder and non-responder group, b) AgeEval1 = age at first evaluation, c) MPOEval1 = months post-onset at first evaluation, d) TypeAphasia = type of aphasia, e) AQ1_100 = Aphasia Quotient score at first evaluation, f) BNT1_60 = Boston Naming Test score at first evaluation, g) Rav1_37 = Raven's Progressive Matrixes score at first evaluation, h) CCRSA1_40 = Communication Confidence Rating Scale for Aphasia at first evaluation

Further examination of the 26 non-responders (less than 5-point change on the WAB-R AQ), indicated that there were only nine participants (11% of the total number of participants) who did not change on any of the language and patient- and family-reported outcome measures. One non-responder of the 26 in this program had an initial WAB-R AQ score of 91.4, thus approaching ceiling and the cut-off of 93.8 for the presence of aphasia; after the ICAP, a change score of four points was recorded. Three other non-responders were in the severe range (0-30 on the initial WAB-R AQ) whereas four were in the mild range (61-90). Only one participant was in the moderate range of severity (31-60). Three participants demonstrated decreased self-ratings after participation in the ICAP. This may reflect a better understanding of the impact of their deficits or they had not fully understood the questions initially and rated themselves too high initially. The family members of these nine participants also rated minimal change of less than 12 points.[89]

3.5 Discussion

The primary aim of the paper was to examine whether demographic and aphasia-related characteristics contributed to response to treatment following participation in one particular ICAP. Results from the logistic regression show that a model of factors cannot be created based on the variables which were included. A younger age was the only variable found to have significantly contributed to greater response to treatment and also was significantly different based on t-tests between the groups (a mean of 52 years compared to 60 years of age). Number of months post-onset after participation in an ICAP was found to be significantly different between the groups on independent sample t-test. The non-responders averaged slightly less than a year post onset and the responders were close to a year and a half post-onset. Thus, responders tended to be younger and started the program at a slightly later time post-onset. A systematic review of intensive treatment indicated there were more drop-outs in intensive research subjects.[123] Brady et al noted in a sub-acute trial that 30 patients enrolled of 102 patients who met inclusion criteria, and only 17 completed the study.[46] In contrast, this ICAP had a 98% completion rate with only two participants who dropped out during the last week of the program due to hospitalizations. Additionally, 43% of first-time participants entered this program at more than one year post-onset, up to five years post-onset (n=36). As we found, non-responders enrolled in the ICAP at a significantly shorter time-post onset; however, this did not seem to be a factor that predicts response to treatment, but perhaps persons with aphasia are better able to tolerate an intensive therapy schedule at a greater time post-onset.

These results may not be generalizable to other persons with aphasia as the persons who take part in ICAPs have sought out treatment and are willing to travel and invest significant amount of time and money to participate.[3] Overall, these results are positive as approximately 70% of participants can expect to show response to treatment on the WAB-R AQ results. This is comparable to previous research on ICAPS, in that the majority of participants see improvements in at least one area measured.[55,57,73,74] As other research has reported that most participants make gains in at least one area, we looked more closely to see how many participants did not make gains on any impairment and participation measures. In the nine participants (11%) who made minimal changes across the outcome measures, there was no apparent pattern, as eight participants were rated at both ends of the severity spectrum and one participant fell in the moderate range. The contrast in the severity levels of the non-responders may indicate different reasons for non-responsiveness to treatment with severe or significant apraxia impacting the more severe participants and

the less severe participants had diagnosis of fluent aphasia. With only nine participants, it is hard to make conclusions regarding what factors may contribute to a person's recovery.

One aspect of examining responders and non-responders which needs closer attention was the decision to look at only one impairment measure and choosing a cut-off score. This was based on limited prior research and more discussion is needed as to whether a ±5-point change score on the WAB AQ was the best outcome measure to use. A large percentage (65%) of non-responders and family members rated themselves or the participant positively on participation measures after the program, even if impairment measures did not change. A broader scope of what constitutes a responder may identify those persons whose changes are not captured by impairment measures. The International Classification of Functioning, Disability and Health (ICF) suggests that evaluating impairment and activity/participation provides a more complete picture of a person's abilities.[70] Worrall and others found in qualitative interviews that persons with aphasia identified goals that aligned with the WHO-ICF in terms of activity/participation.[18] A responder could be defined as a participant who demonstrates significant change in one impairment measure and one activity/participation measure. It may be necessary to ask participants what outcome measures are important to them and individually determine responders as those who made improvements in the areas they identified as important. The Hawthorne effect may be a factor to consider as participants and families have spent time, money, and energy to take part in such a program and may feel obligated to report improvement either to the program or to reassure themselves that the return on their investment was notable.[124] Other factors external to the person with aphasia have not been examined in ICAP participants. Perhaps stronger social networks, supportive families, and community resources may be different in those who seek out intensive treatment. Given that ICAPs are comprehensive by definition, using one impairment measure provides a very narrow picture of response to treatment and does not account for those participants and family members who reported positive changes on participation measures.

Since we were unable to determine a model of factors that contribute to response to treatment and previous research has reported inconclusive results regarding which factors predict recovery, this leads to more questions regarding what other factors may be important for prognosis and recovery. These range from micro-level gene expression factors to macro-level demographic and personal characteristics factors (e.g., age, overall health status, exercise habits, and pre-morbid psychological state). In terms of micro-level changes that

occur, researchers are beginning to explore how brain-derived neurotrophic factor (BDNF) plays a role in recovery from stroke and traumatic brain injury (TBI).[125-128] BDNF has been found to be an important neurotrophin for neuron survival, genesis, repair and recovery.[125] There may be an interaction of the micro and macro levels. Researchers found that mice isolated immediately following stroke produce less BDNF and show more histological damage and depressive-like behavior than mice that interacted with other mice.[129] Isolation following aphasia may affect BDNF at the micro-level which appears behaviorally as depression which can then affect response to treatment at the macro-level.

Research in the cognition and TBI literature may provide some insight in prognosis in aphasia. Alteration of the human BDNF gene has been identified as playing a role in predicting cognitive recovery and outcome following penetrating TBI.[126] The prevalence of concussions in athletes has highlighted how late effects may impact subsequent neurological injury later in life. Moretti and colleagues discuss implications of prior TBI which can later affect cognition in older adults.[130] Pre-morbid TBIs may impact recovery in aphasia by negatively impacting neuronal recovery. At a macro-level, cognition is typically not assessed in persons with aphasia and may have implications in identifying better responders to therapy and which type of therapy provided.[131] Another factor which is generally not measured in aphasia research but may have implications for recovery is aerobic exercise training as Chin and others found that vigorous cardiorespiratory exercise led to greater improvements on cognitive tests in patients with TBI.[132] It also appears that BDNF and cognition can be mediated by exercise.[133] Given the physical limitations of hemiplegia, it may be a challenge for persons with aphasia to engage in the same kind of vigorous exercise which appears to have a positive effect on BDNF which in turn may positively impact cognitive recovery after brain injury. While cognition is generally thought of as a holistic brain function that cannot be improved upon, it appears cognition can be mediated positively or negatively with interactions at the macro-behavioral and micro-neuronal levels.

Additional genes may also be implicated in prognosis and recovery from aphasia but not directly related to aphasia components. Polymorphism of the ApoE ε4 gene may contribute to variability in recovery after stroke and is associated with atherosclerosis and significantly poorer recovery in the first month.[134,135] Van der Lely and colleagues discuss the FOXP2 gene which is implicated in specific-language impairments in children.[136] How mutations in FOXP2 carry-over into adulthood and impact prognosis and recovery from aphasia is not yet known. Much more research is needed to examine the role of gene expression due to

neuronal injury and how pre-morbid alterations in gene expression might impact response to treatment.

3.5.1 Limitations

The major limitation of this study is that the data are derived from a clinical program and there was no comparison with control subjects typical of a research study. The participants were a self-selected sample and the treating clinicians administered the pre- and post-treatment evaluations, thereby, potentially introducing assessor biases. However, since ICAPs have been in operation for several, if not many years, it is important to evaluate outcomes as participants and families are seeking out intensive treatment.

3.5.2 Clinical implications

It is important for stakeholders to note that the percent of persons who did not make gains in any area that was measured is reported at approximately 11%, However, we do not know how those participants might have responded to different outcome measures and may show improvements in other areas. Most persons with aphasia do respond to treatment after taking part in an ICAP. The caveat is that we do not know exactly which factors contribute to improvements since this research study was unable to model the contributing factors.

3.6 Conclusion

Findings from this research study were unable to identify a model of factors which contribute to response to treatment for those participants who were considered responders. The groups were not significantly different in terms of gender, type of aphasia, naming, non-verbal cognition or confidence. Only one factor was identified, age, which implies that being younger contributes to someone responding to treatment and was significantly different between the groups. There was a significant difference in months post-onset, approximately six months, between responders and non-responders; however, this didn't not appear as a factor in the logistic regression model. Future research may examine whether persons with different severity and types of aphasia identify different outcome measures or goals. A person with more severe aphasia may identify activity/participation goals, whereas, someone with less severe aphasia may have specific impairment goals and vice versa. The person could identify impairment and activity/participation goals as equally important. It may also be important for participants to rate the importance of impairment and participation skills and outcome measures and then identify responders versus non-responders based on achievement of individually identified outcomes.

4.0 Chapter Four: Clinician perspectives of an intensive comprehensive aphasia program (I-CAP): Intense, rewarding and challenging

Chapter Four aimed to explore the experiences of clinicians taking part in an Intensive Comprehensive Aphasia Program (ICAP). Clinicians were interviewed and the interviews were transcribed and coded for themes. The contents of this chapter were published as a manuscript, Clinician perspectives of an Intensive Comprehensive Aphasia Program. *Topics in Stroke Rehabilitation*, 20(5), 398-408. Babbitt EM, Worrall LE, Cherney LR. (2013). Appendix C).[3]

4.1 ABSTRACT

Background: Intensive comprehensive aphasia programs (ICAP) have increased in number in recent years in the U.S. and abroad. This specialized therapy model provides treatment that differs from usual care. It is important to understand the perspectives of clinicians who provide the treatment and are stakeholders in the process.

Objective: To describe the experiences of clinicians working in an ICAP.

Methods: A phenomenological approach was taken. Seven speech-language pathologists from three different ICAPs were interviewed in person or on the phone. Their interviews were transcribed and coded for themes relating to their experiences.

Results: Clinicians described three major themes of working in an ICAP. The first theme related to the intensity component of the ICAP that allowed clinicians to provide in-depth treatment and provided them with a different perspective with regard to providing treatment and the potential impact on the person with aphasia. The second theme of rewards for the clinicians included learning and support, seeing progress, and developing relationships with their clients and family members. Thirdly, challenges were noted in the time involved in learning new therapy techniques, patient characteristics such as the chronicity of the aphasia and the difficulty of returning to work in typical clinical settings after having experienced an ICAP.

Conclusions: Although there is a potential for bias with the small sample size, this qualitative pilot study gives insight into the clinician perspective of what makes working in an ICAP both

[3] The content included in Chapter Three is identical to the accepted manuscript, however, it has been modified to match the formatting of this thesis document (including reference style). As such, the number, size and positioning of figures and tables is different to that of the published version.

worthwhile and challenging.

4.2 Introduction

In response to consumer request for additional services, there has been an increase in the number of intensive comprehensive aphasia programs (ICAPs) over the past several years.[50] ICAPs provide a minimum of three hours of therapy a day for two weeks, with several programs providing as many as 4-6 hours a day over a period of 4-5 weeks. Daily therapy typically includes multiple individual sessions, group sessions, computer sessions and/or community outings. This model is quite different from the "standard" therapy model of outpatient rehabilitation in which a person with aphasia usually receives 2-3 hours of therapy a week over a period of 8-12 weeks.[50] Therefore, a person in an ICAP program may receive as much as 120 hours of focused language therapy over a month. A person in a "standard" therapy model will receive approximately 8-12 hours of therapy in a month. Other studies have described the effects and outcomes of such intensive therapy on people with aphasia.[55,57,74] What has not been studied is the effect on the speech-language pathology clinicians who deliver this new service. What is their experience with ICAP's?

Several studies have begun to explore the clinician's perspective in providing treatment to persons with aphasia. Two studies have provided insight into clinicians' experiences with goal setting with their clients. Sherratt et al interviewed clinicians about the process of developing treatment goals and found that clinicians included a variety of factors when identifying goals and that the goals spanned the WHO-ICF.[139] The goals of their patients with aphasia and family members were then compared to the goals of the speech-language pathologists and tensions or differences between goals were identified. Rohde et al also compared clinician and client treatment goals to explore the similarities and differences.[19] Through interviews, they found that clinicians focused more on impairment-based goals. However, their clients' perspectives differed as their goals focused on returning to functional and valued activities. In another study by Brown et al, clinicians were interviewed about what they think it means to live successfully with aphasia.[66] They also compared the perspectives of persons with aphasia and family members with the clinician views. While they found some aspects were similar, the meta-analysis highlighted different perspectives clinicians may have and the importance of exploring the perspectives of all stakeholders. Hersh's interviews with clinicians highlighted their struggles with the act of terminating therapy. Clinicians reported challenges of coping with real versus ideal endings, building and breaking relationships, and promoting client empowerment versus professional control.[137] Hinckley used another type of qualitative inquiry, auto-ethnography, as a method to analyze

her own clinical skills and judgments through self-reflection.[138] She remarked that discussions about clinician's own subjective experiences are an important part of the clinical process. Qualitative studies have demonstrated that reporting on clinician experiences provides information that is typically not included when evaluating aphasia treatment. These views are important and may help shape the process of providing aphasia treatment.

The experience of clinicians working in an ICAP may be different from their experience with standard care for several reasons. These include the intensity of the program and a broad range of competency with the multiple treatment approaches that are required to ensure that the ICAP is comprehensive. Several ICAPs have also been developed within the university sector and are likely to include more experimental and novel treatment procedures. Exposure to non-standard but evidence-based therapies may also have an effect on the experience of the ICAP clinicians. Both positive and negative clinician experiences of working in an ICAP need to be explored for the sustainability of the ICAP workforce. Hence, the aim of this study is to describe the clinician experience of working in an ICAP using qualitative research methodology.

4.3 METHODS

4.3.1 Design

This exploratory qualitative study is based on a phenomenological approach which "describes the meaning for several individuals of their *lived experiences* of a concept of a phenomenon."[59,60] This study attempts to understand the commonalities and possible differences of several clinicians' experiences in a non-standard clinical treatment program. The phenomenological approach allows clinicians who took part in a particular experience to give their own interpretation of events as providers of a specific clinical treatment. Semi-structured interviews allow for the interviewer to guide the discussion, but more importantly, for the participant to share thoughts without constraining ideas.

4.3.2 Clinician participants

A purposeful sample of seven speech-language pathologists is consistent with the number of participants suggested for phenomenological research (i.e., 5-25).[59] Speech-language pathologists representing a range of characteristics were sought for these interviews. They differed in the number of years working, previous participation in ICAPs, geographical locations in the US and abroad, and type of clinical settings. The clinicians were recruited through the Director of each ICAP. All participants signed an IRB-approved consent form.

Table 4.1 shows the clinician and program characteristics as well as the experience of the interviewer and researcher. Years of experience ranged from three to 29 years. Number of times participating in an ICAP program ranged from one to more than 15. Clinicians were interviewed from three different facilities, two in the US and one in Australia.

Table 4.1. Clinician characteristics

Clinician	Years working	# ICAP sessions	ICAP location; times per year	Typical work setting
1	9.5	4	Non-profit rehabilitation hospital; 2x a year	Day Rehab
2	29	3	Non-profit rehabilitation hospital; 2x a year	Day Rehab
3	4	2	Non-profit rehabilitation hospital; 2x a year	In patient
4	5	1	Non-profit rehabilitation hospital; 2x a year	Out-patient
5	3	13	VA hospital; 6x a year	ICAP; outpatient
6	4	13	VA hospital; 6x a year	ICAP; outpatient
7	7	1	University clinic; 2x a year	Current: ICAP; PhD candidate Previous: Inpatient
EB; interviewer	15	7	Non-profit rehabilitation hospital; 2x a year	Research; ICAP

4.3.3 Data collection

The interview questions were developed during discussions among the authors and another experienced clinician from an ICAP. See Table 4.2. A variety of question formats were implemented to encourage clinicians to think about different aspects of working in an intensive program. Both open-ended questions and modified free-listing prompts were given.[140] The interview started with obtaining background information about the clinician (i.e., how long they had been working, in what types of settings, and prior experience with persons with aphasia). Then, the clinicians were given the opportunity to talk about their experiences working in an ICAP with an open-ended prompt. Next, they were asked to free-list adjectives to describe their experiences. The topics and ideas they generated were used as segues to expand those ideas. The order of the questions served only as a guide so that the conversational nature of the interview was preserved. The questions were not sent to the clinicians before the interview. The first author (EB) interviewed all seven clinicians. The interviews ranged from 27 minutes to 62 minutes (mean number of minutes=45, SD=15).

The interviews were digitally-audio recorded and transcribed by the first author or a trained volunteer. Each clinician was given the opportunity to review her own transcript after it had been transcribed and to make changes or add information.

Table 4.2. Questions and prompts for interviews

General Work experience questions:
How long have you been working?
Where and what types of settings have you worked?
What is your prior experience with aphasia?
Interview Guide:
Tell me about your experience in ICAP program.
Give some adjectives to describe working at the ICAP.
What are the challenges?
What are the rewards?
As a clinician, compare the ICAP to your typical clinical workload?
Why did you choose to work during this ICAP?
Why did you come back?
Would you do it again?
What did you learn from this experience?
Any thoughts about the participants?
What do you think are the most important features of the IAP?
Give three positives of working at the IAP.
Give three negatives of working at the IAP.
What characteristics do you think an SLP should have to be a successful clinician in the program?

4.3.4 Analysis

Analysis of the interviews followed Graneheim & Lundman guide to methodically review interview data. Each transcript was read through in its entirety by the first author at least twice to gain familiarity with the content.[141] Responses were chunked into meaning units (responses to each question) and then broken into condensed meaning units (i.e., fillers, repetitions, etc. were removed). A condensed meaning unit consisted of a thought or idea. This was further condensed to the “essence” of the thought, that is, the phenomenological unit of analysis.[141]

Four interview items were chosen to analyze and present in this paper. Responses to these specific questions summed up the experiences of working in an ICAP and the clinician perspectives. Those questions were:

- Tell me about your experience in ICAP program.
- What are the challenges?
- What are the rewards?
- As a clinician, compare the ICAP to your typical clinical workload.

The clinician responses to these core items were extracted and analyzed to determine if there were common themes across the interviews. The entire transcripts were reviewed again to obtain additional quotes to support the main themes and sub-themes.

4.3.5 Reflexivity and Rigor

Houghton describes four approaches to reflexivity and rigor: credibility, dependability, confirmability, and transferability.[142] Credibility is enhanced through prolonged engagement, peer debriefing and member checking. Prolonged engagement occurred as the interview progressed. The first author would ask the clinician "Anything else?" if the clinician appeared to be finished with a thought. Each clinician had the opportunity to talk as long as she seemed to indicate she had thoughts regarding the particular question. Clinicians were also offered the opportunity to contact the interviewer at any time in the future if they had additional thoughts on their experiences. Peer debriefing took place as the second and third authors reviewed the coded interviews for confirmation of the first author's interpretation of the data.[141] Member checking was accomplished by having the clinicians review their own verbatim transcript. Transcripts were emailed to each clinician and they had the opportunity to modify the content if they wanted. Only one clinician had a minor change in her transcript.[143] Clinicians did not have the opportunity to review the themes once the analysis was completed. This may have provided additional data and new insights into clinicians' interpretation of themes that other clinicians have discussed. This step might be considered in future studies if there was disagreement amongst clinicians about their experiences working in an ICAP, but there was a general consensus about themes in this sample.

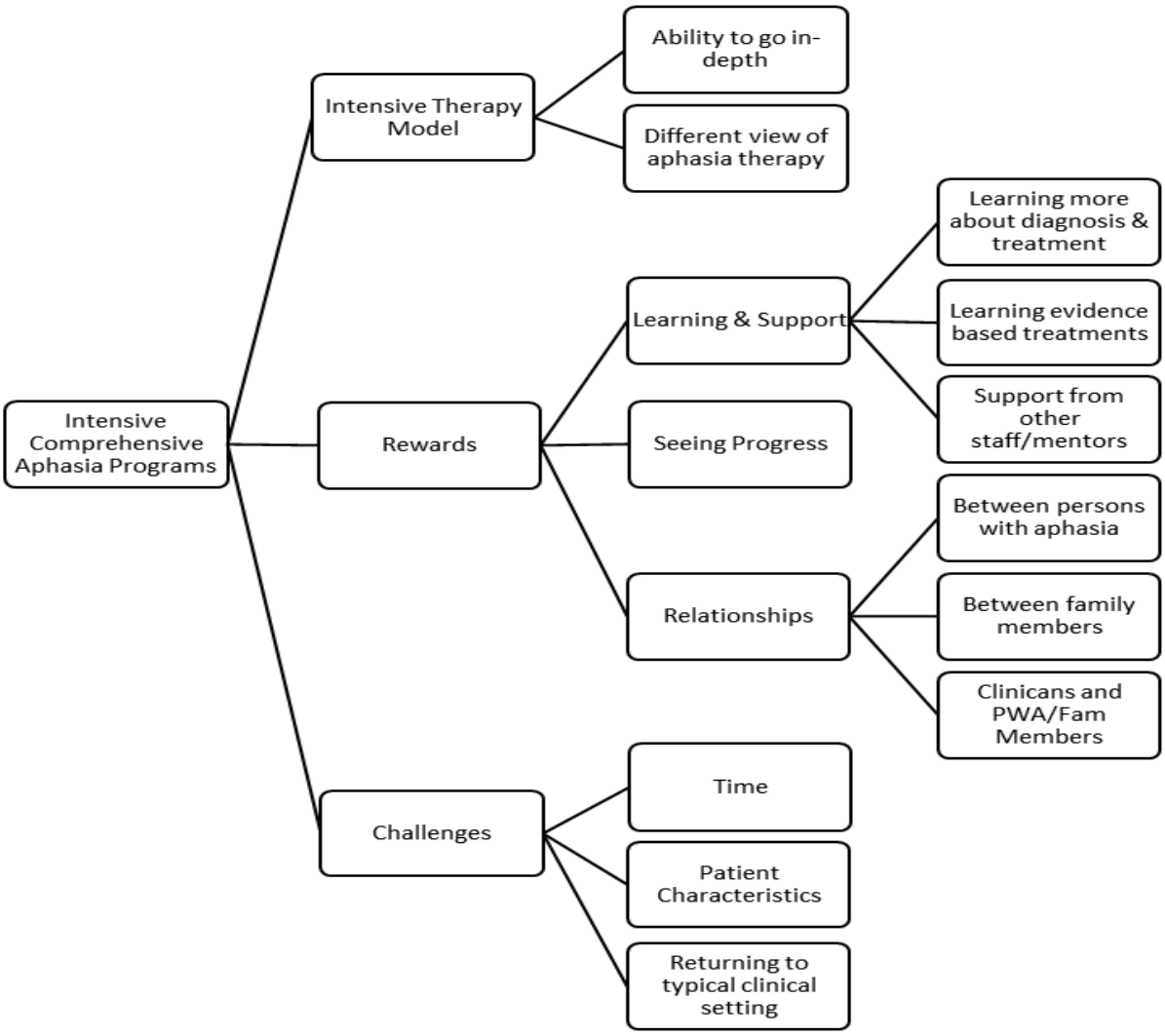
Dependability and confirmability were considered throughout the process of analyzing the interview material. The first author kept an ongoing record of her reflections and experiences to provide a method of practicing reflexivity.[144] Additionally, an audit trail was performed as each interview was transcribed, condensed, condensed further and then coded for meaning. This type of document was created for each interview and then used for review and analysis

by all three authors. Transferability was explored by providing thick descriptions of the interviews and analysis, and which are presented in the following sections of this article. The ability to present a range of viewpoints enhances the rigor of the data and analyses.[144]

4.4 Results

Clinicians described their thoughts about working in an ICAP, the difference from typical clinical settings and their personal rewards and challenges. Sometimes the sub-themes were explicitly stated in response to a question, whereas other times the theme emerged during another line of discussion. The interview format and questions guided the discussion but clinicians brought up different themes at different points in the interview. For example, one clinician reported that learning and support were rewards in response to the opening inquiry “Tell me about your experience working in an ICAP”. Another clinician described the same rewards in response to the question later in her interview, “What are the rewards for working in an ICAP?” The results below describe the three main themes and sub-themes that emerged from the selected interview items: clinicians’ thoughts about intensive therapy and their perceived rewards and challenges (see Fig. 4.1).

Figure 4.1. Themes extracted from clinician interviews about working in an intensive comprehensive aphasia program (ICAP)



4.4.1 Intensive: a different therapy model

In exploring the intensive therapy model from the clinician's perspective, two sub-themes were discussed that led to perceived differences in working in an ICAP versus a typical clinical setting. The ability to go *in-depth* with their therapies was an important sub-theme as clinicians noted that the sheer number of hours of therapy provided a platform for meaningful gains seen as a result of the therapy. The clinicians used terms like "dig in" and "fine tune", "a different level of understanding" with regards to the intensity of the treatments they provided. Most clinicians indicated they were not able to provide that kind of in-depth treatment when treating someone only a few times a week for a few weeks. A second sub-theme was that working in an ICAP provided a *different view* of aphasia and aphasia therapy. Clinicians reported that their views changed regarding patients making progress at more chronic stages. They also commented on changes that they would make in their own clinical

practice which included more focused therapy on one task or increasing the number of trials per session.

Table 4.3. Intensive therapy model: examples of quotes

1. *Ability to go in-depth:*

- "When you're in the intensive it's almost the most optimal treatment setting you can ask for so you can really dig in."
- "because you're seeing them intensively, you just have that opportunity to get such a deeper understanding of what's going on."
- "You're really fine tuning… the treatments which is great. It's something that we never, we don't get a chance to do, certainly in inpatient when somebody's there for two weeks or three weeks."
- "With the time factor you're getting in a lot more trials. You have the ability to… shape and fade your cues and modify your protocol on what you're seeing because you're seeing them for such a lengthier period of time."

2. *Different view on aphasia and aphasia therapy:*

- "The concept of… the intensity of a single repeated practice on a certain goal is really important"
- "If I only ever saw aphasia from an inpatient perspective… even from day rehab or outpatient, I would just have a completely different view of its effect on somebody's family or effect on that person or the potential for somebody to make really great progress, too."
- "I've learned to focus my treatment… I've learned that… intensity is important. I think that will change how much home practice I give patients… I think I will spend more time training caregivers to do things at home because I… saw firsthand what… the intensity component does."
- "In comparing to… other people with aphasia that you see one or two times a week… people tend to sign off quicker because… the progress is minimal and… speech pathologists might think that their patients are plateauing when it's just that they haven't been able to see them often enough to see enough progress to… rationalize to continue the treatment."
- "We had group sessions every day… it really reinforced [for] me how important groups are for patients."

4.4.2 Rewards

The rewards for working in the intensive programs were many. The clinicians interviewed used the words “honored”, “privileged”, and “a gift” to describe their experiences of working in an ICAP. There were several sub-themes to support the theme of Rewards for working in an ICAP: *Learning and Support*, *Seeing progress*, and *Relationships*. Additionally, some clinicians described personal benefits which were not themes across all participants, but provided insight into working in an ICAP. One clinician stated that being part of something unique and special made her unique as a clinician. A few clinicians felt that working in an ICAP program provided them with variety and a change of pace which led to them feeling “refreshed” when going back to their “regular” jobs.

Several clinicians identified learning about evidenced based therapy techniques and being able to use them in their regular clinical setting as a reward. Gaining support from more experienced colleagues was also mentioned as a reward. This contrasted with limitations due to time constraints or lack of mentors in their typical clinical settings which limited their opportunity to collaborate or learn from senior clinicians. One clinician mentioned that access to and collaboration with experienced staff allowed her to grow professionally and become a better clinician. Learning about aphasia in terms of diagnosis and treatment was included in this sub-theme. Several clinicians mentioned bringing new therapy techniques back to their clinical practice. Three mentioned having the time to read research articles, trial and implement the therapy technique and ask questions about it were positive factors of the ICAP. Four clinicians commented about being surprised or insecure that they didn’t know the information about some of the different therapy techniques. One clinician described the fact that she didn’t know the current evidence-based therapy techniques as humbling. She also reported that working in an ICAP gave her the opportunity to learn how to better implement a therapy technique. Learning and support from other therapists and more experienced therapists were common statements among the clinicians.

The clinicians indicated that the progress of clients demonstrated that they were “good” clinicians. They used words like “fulfilling”, “rewarding”, and “gratifying” to describe how they felt when their patients made progress. In that sense, the progress seen as a result of intensive therapy validated the work they did as clinicians. They commented that it was not only the progress measured during the evaluations, but that seeing their patients accomplish personal goals was rewarding to them. It was also important to clinicians that the persons

with aphasia and their families saw progress as well. This was another source of validation that they were doing good work as clinicians.

Additional rewards were explored through describing their relationships with the patients and their family members. Clinicians commented on the different kind of relationship they had with the participants they worked with. Two clinicians remarked that they kept in touch more often with participants from ICAPs. The clinicians indicated that they heard from the participants not only when they were doing well, but also when things were challenging. Additional aspects of relationships, which differ from typical clinical settings, were camaraderie and support that the care-givers provided each other. Clinicians noted that it was difficult for family members to meet or form relationships in typical clinical settings. ICAP settings provided the opportunity for relationships to develop between the participants with aphasia as well as the families. They noted that there was more “bonding” that happens because of the time and proximity factors inherent in the intensive models.

Table 4.4. Rewards: examples of quotes

1. *Learning and Support:*

- "I think having the drive to always want to learn more and gain more knowledge and find out what's new in the field… new and upcoming, is kind of crucial."
- "It's something that I felt when I was in grad school. There was this huge emphasis on… really kind of dissecting the person's impairments and figuring out how to approach it or looking at the evidenced based practice… in the real world it just doesn't always happen that way… So having this ability to take a step back where you… have to use those thinking skills again… you have to really problem solve and think of things in a different way. I thought was just really great."
- "All of those treatment techniques we used are things that I didn't use… I didn't use them before and now I do… I was…embarrassed or felt bad that I didn't know about and wasn't using before."
- "It just makes you a better clinician, makes you a better professional."
- "Just talking about… the clinical problem solving… is very useful as well as… having… the ability to go into such depth with each patient and having other speech therapists right there to assist in the planning and determining treatment recommendations."

2. *Seeing Progress:*

- "It's just also really fulfilling to work with somebody for that period of time, that intensity, and really be able to see some of the changes that they make."
- "Patients improved so much. It was great to see that. I don't always see that particularly in outpatient with people who have chronic aphasia… That's a huge reward to see that on the last day… realizing these improvements, seeing their test scores. Seeing this is where I was, this is where I am."
- "It's one of the few times a year I actually see them make improvements within you know that amount of time. Within the month we see them, you definitely see things. I've had patients who… wanted to just be able to read something again and they're reading and for their face to light up and for them to tell you "I can finally read again" and they you know get emotional sometimes… I've had family members too who are surprised at the end… when they see their family member write a word and they haven't been able to write anything for the past five months… being able to see the gratification that our patients feel and their family members feel is huge."

3. *Relationships*

- "I didn't get this in day rehab or inpatient but you have 10 people there with aphasia (and you're really getting a chance to see the variety of difficulties that people have and their family situations and all of the social dynamics that happen as well) as when those people all come together in one group and how rewarding it is for them to be able to have this.. bond with each other."
- "Aside from the… therapeutic improvements, I think improvements in quality of life… meeting other people with aphasia… it was really rewarding to see some of the first time participants… interact with other people with aphasia… seeing them form new relationships."
- "… how [family members] kind of benefit from each other being around as well as just being able to see their family member be so independent in certain situations."
- "Clinically, you wouldn't get a group of family members together to talk… it's hard, often hard to meet family members… in a really acute environment."
- "You develop a bond with somebody when you're working with them for five and a half or six hours a day… when you're in a clinic and you're seeing… anywhere from four to eight patients a day… there's just less opportunity to really… develop that relationship with your patients and take it that one step further."
- "I still talk to so many of these… guys and their family members and just hearing these little things [updates]… it makes your day."

4.4.3 Challenges

Clinicians reported many challenges to working in this different clinical model. One major sub-theme was *time*. The difficulties with the time aspect ranged from more physical time writing reports to more mental time they spent thinking about their patients or therapy tasks outside of the routine day. However, the difficulties were off-set by comments like, "what you get out of it is gonna be so much more than the extra time that you put in." Another sub-theme described the challenges related to *patient characteristics and expectations*. More severe patients could be more challenging as well as those patients and families who have high expectations of recovery after participating in an intensive therapy program. A third sub-theme related to clinicians comparing the "ideal" intensive therapy model to typical therapy settings. After seeing the amount of progress that could be made, clinicians remarked that it was hard to go back to work in typical settings with many limitations in providing therapy.

Challenges with time ranged from the time spent thinking about and planning the therapies, reading current research articles about evidenced based practices, and meetings with other clinicians and mentor staff to discuss patients and treatment approaches. Some clinicians reported thinking more about patients in their off time, including dreaming about their patients. It was evident that these therapists felt that the rewards for putting in the extra time were worth the additional time as it enhanced their clinical skills and contributed to the gains they saw patients making.

Clinicians talked about difficult patients that challenged their clinical skills even within the framework of an intensive program. Personality clashes that occur in regular clinician settings can also occur in intensive programs; however, most clinicians talked about how the ICAP participants were more motivated and willing to work. A few clinicians talked about some of their patients who were more chronic and presented challenges. The expectations for recovery had to be discussed with the participants and the family members. One clinician felt that it was difficult to provide new and different therapy ideas for those who were farther post onset and had already participated in extensive therapy. Clinicians also described the difficulty working with aphasia in general, but especially in an intensive program with many hours of treatment and how challenging it is to individualize the treatment protocol.

Many clinicians reported challenges in returning to a typical clinical setting after working in an intensive program. Many felt the intensive setting was ideal for providing therapy that maximized progress. Clinicians remarked on the factors that play into why they saw greater benefits with the intensive setting. Some of these issues were mentioned previously. The thread that ran through all the clinicians' comments was that they felt the intensive setting was superior to typical settings and the dilemma for the clinicians is that the intensive program is not available to all their patients.

Table 4.5. Challenges: examples of quotes

1. *Time spent working or thinking about therapy tasks*:
   - "Paperwork and goal setting was time consuming… want them relatable and functional and individualized."
   - "it took more time to come up with treatment plans and determine the best next step. It was just more time consuming to do that in the intensive program than it is

in my every day treatment. It was challenging learning and then using for the first time these new treatment techniques. All these are good challenges."

- "… it's a really different way of thinking about working with somebody… It's like my brain has to do so much more for any given day during the during the intensive than it does in inpatient… it's more just thoughtful in trying to plan and carry out that much therapy for a given person in one day and trying to take some of the evidenced based approaches and incorporate those into sessions… and to really… problem solve and think 'well my participant can't do it this way how could we modify it?' so that's where I think the challenge comes from. It's just much more brain power involved, maybe not more but just a different kind of brain power."

2. *Patient characteristics:*

- "You have your type-A personalities who want perfection. They expect to be cured when they come, especially when they're coming to this program. Can be challenging to find that balance between having them realize what's realistic expectations versus in being cured."
- "There's a huge difference in their motivation and … they bring that to therapy… I'm not waking them up in the morning telling them you have to do therapy right now. They're coming to see me and this brought it to a whole different level. Patients are paying a lot of money to be there. It's a big time commitment. They're motivated. They're there to work."
- "I think they tend to be a little bit more outgoing, a little bit more active, involved in their community, involved… socially. Some of them want to continue to work. Whereas… some patients who I just see as an outpatient one time a week, I think they tend to be a little bit more isolated at times. They're a little bit more depressed even."

3. *Returning to work in "typical" clinical setting:*

- "…There are so many things stacked against you sometimes in your day to day job. Sometimes the patients aren't always invested. Sometimes even when the patient's invested, you can only get so much because there's not enough family support at home. But whereas the intensive… they're gonna have family support and they're there to work so you just… cut through all that extra stuff."

- “Whereas the demographics at day rehab, there’s a lot more lower income people… so that’s too bad because… the intensive is… a really good program that it’s too back that it can’t be more accessible to everybody.”
- “I just get a lot more gratification and satisfaction out of that level of therapy versus seeing somebody… for a couple minutes on the floor… I’m happy… if I can get somebody on an advanced diet… but I don’t feel as much it’s something I’ve done to help them. I feel like it’s just more their medical status has improved… [in ICAP] it’s more of what I’m doing and the research I’m doing and our team is doing to… help this patient is… what makes it more rewarding in the end.
- “you just can’t provide the same quality of care that you do in the intensive aphasia program.”
- “That’s also a little bit of a letdown when you do go back to your job because it isn’t always the ideal treatment setting and it’s a little disheartening to sometimes think [could this person make the same type of gains] if there wasn’t insurance limitations and… if I was able to work with them for two hours individually a day. What could the difference be? So sometimes that’s a little bit depressing.”

4.5 Discussion

These interviews generated a first look at what a small number of clinicians think about the ICAP service delivery model, especially comparing this therapy model with the typical clinical setting. With the increase in the number of ICAPs, more speech and language pathologists may have the opportunity to experience this different therapy model. The aim for this study was to find out what clinicians think about working in an ICAP. Is their experience different from working in a typical clinical setting? What are some of the rewards and challenges? Emerging from this phenomenological analysis, were the common themes that working in an ICAP is hard work, but the rewards outweigh the challenges for these clinicians. It was clear that the personal and professional benefits were many and that the intensive model provided a measure of success for the clinician too. Learning evidenced based therapy techniques was important to clinicians; they felt that it made them better clinicians. Support, being able to problem solve with and learn from other clinicians and mentors were important features. Clinicians reported they didn’t have these opportunities in their typical clinical settings due to time constraints. They felt validated as clinicians when they could see significant progress in their patients and when patients and family members noticed that progress as well. Rewarding relationships were also remarked upon. The programs brought

together people with aphasia and their families and provided opportunities they wouldn't have had otherwise. They felt they were doing their best work in the best possible situation.

Previous research on health professionals' job satisfaction highlights many of the same factors that the clinicians in this study discussed in their interviews. For example, McLaughlin, et al interviewed clinicians about attrition and job satisfaction.[145] They also reported that variety in their jobs, interacting with clients, support and collegiality from working in a team, helping people/making a difference and learning/expanding their knowledge base were the important factors which led to positive experiences working as a speech-language pathologist. Occupational therapists and nurses working in inpatient settings that served patients with eating disorders also reported that patient interaction and building therapeutic relationships were factors that led to job satisfaction.[146] Randolph found that the intrinsic characteristic of wanting to help people overcome disabilities positivity impacted job satisfaction for occupational and physical therapists and speech-language pathologists.[147] The sub-themes of learning, support, seeing progress and developing relationships contributed to the rewards for the ICAP clinicians and the perception that they were better clinicians because of the experience.

While challenges were noted, mostly related to the time intensive factor with either learning new techniques quickly or having to think more about the therapy protocols, clinicians reported the rewards off-set those particular challenges. Similar themes related to challenges have been noted by other rehabilitation professionals including speech-language pathologists working in other settings. McLaughlin reported that negative aspects of being a speech language pathologist included feelings of limited or uncertain clinical efficacy.[145] In contrast, clinicians in our study mentioned that working in the intensive program reduced the feelings of limited efficacy they felt in typical clinical settings. In discussing job satisfaction, school-based speech-language pathologists reported challenges that contribute to perceived stress: lack of opportunities for professional development, decreased time and workload management.[148] They also reported that additional stressors were related to scheduling/workload issues or limited effectiveness due to client characteristics which then led to limited progress. The ICAP clinicians we interviewed felt that working in an ICAP reduced or eliminated those stressors to a certain degree. Although these stressors may be inherent in all therapeutic work environments, the model of intensive therapy may reduce the challenges clinicians face. Clinicians in our interviews noted that they felt they were making a difference and were able to see successful progress. They also

noted that it was difficult to go back to their "regular" job in which they didn't see the same kinds of progress.

Hence, the predominantly positive experience of ICAPs by clinicians reflects the generally positive ICAP outcomes for participants and their families. ICAPs are likely to continue to grow in number with the recent increase in number of programs. Rose and colleagues noted in their survey of ICAPs that of 12 programs, seven had commenced in just the three years prior and the other five had been in operation for an average of 11 years.[50] There have also been several studies recently published that show a positive effect for increased intensity.[57,73,112,149-151] Hence, clinicians are likely to view an ICAP as a means of providing increased intensity of treatment. This study suggests that other clinicians may find working in an ICAP to be a positive experience as well. The challenges experienced by clinicians; however, are not easily overcome. The pressure of time is inherent in any intensive therapy program, as is the challenge of responding to all types of participants. Changing models of practice and therapies when clinicians return to their typical work settings can also be a challenge. Clinicians indicated they felt they were better clinicians for having experience in an ICAP. Carry-over of their enhanced clinical skills may ultimately improve service delivery for aphasia rehabilitation.

4.5.1 Clinical implications

As several clinicians stated, the ICAP experience was like going back to school. One clinician even stated, "but it was even better because you were reading the current evidenced based therapies, implementing them, and then talking about how it went." Clinicians talked about how they altered their own clinical practice, by emphasizing home practice, or providing massed practice during sessions, or by teaching others at their sites how to implement some of the evidenced based practice techniques. One clinician mentioned that prior experience with aphasia was important because "you aren't there to learn about aphasia, but to build on what you already know". ICAPs, therefore, have potential for professional development and specialized skill training for novice and experienced speech-language pathologists. A potential solution to the time pressure issue of needing to quickly learning new therapy protocols is to develop training modules that are related to the ICAP therapy protocols. Discrete skills could be learned and practiced prior to commencement of the ICAP and intensive therapy protocols incorporated into training programs for ICAP clinicians. Clinicians recognized that patient progress had a direct impact on their own feelings of being valued as a therapy provider. It was telling that clinicians

mentioned terms like “depressing” and things were “stacked against” them when talking about returning to typical therapy settings after working in an ICAP. Organizations may want to look at how typical therapy settings can recreate specific factors from ICAPs to enhance patient progress and clinician job satisfaction.

4.5.2 Future considerations

We have reported on themes discussed by clinicians in three different ICAPs. Although themes were consistent across clinicians, there were also some differences between the ICAPs. Future research regarding ICAPs may need to consider how differences in the programs may impact perceptions and outcomes. For instance, of the three programs represented by the clinicians in this study, one program provides on-site housing for its participants who must be independent in all Activities of Daily Living (ADLs) to attend. Family members do not attend. Therefore, clinicians from this ICAP did not discuss the bonding of family members, but did have the opportunity to observe more bonding between the participants with aphasia. Furthermore, the clinical population at this ICAP might be different given that the participants are more independent and active in the community. Thus, site-specific factors can influence participant characteristics which, in turn, may influence the clinician’s perceptions of working in an ICAP.

Patient characteristics may impact the clinician’s ability to see progress and their overall perception of the ICAP. For instance, one clinician reported difficulty with motivating a young patient with a TBI who was signed up for the program by his parents. She found it difficult to motivate and engage this particular client. Another clinician reported it was a challenge to work with a person with severe chronic aphasia who would have been discharged in a regular setting for reaching a plateau. This notion of plateau was not an important factor to other clinicians who welcomed the opportunity to work with patients with chronic aphasia as they felt the patients were ready and motivated.

Future research must also consider methods to decrease bias. Results of the current pilot study must be interpreted cautiously because of this potential. For example, all clinicians approached agreed to participate in the interview; therefore, we may have excluded clinicians who did not enjoy working in an ICAP. The clinicians may not have revealed their true feelings because they were interviewed by a colleague who had a perceived investment in the local ICAP. Similarly, being interviewed by a clinician from another facility may have biased the clinician to reporting more positive aspects of their experience. The interviewer

may not have followed up on clinician responses as she felt she knew or inherently understood what the clinician meant because she, herself, had been an ICAP clinician. The language and terminology used in the interviews may have been constrained because the clinicians and interviewer were all speech-language pathologists. On the other hand, this may have been a benefit during analysis of the transcripts because the first author may have perceived subtle nuances due to shared experiences. A factor that may impact generalization of clinician's experiences is that clinicians who work in an ICAP as part of their regular job duties may have different experiences than clinicians who participate occasionally. The staffing structure of the intensive program may impact a clinician's perceptions. Clinician training may be another factor that is specific to an ICAP program.

4.6 Conclusion

This study has described what some clinicians see as important elements in the composition of Intensive Comprehensive Aphasia Programs. The structure of an intensive comprehensive aphasia program may provide ways for clinicians to feel they are doing their best work. They reported seeing more progress, developing deeper relationships with their clients and family members, and seeing deeper relationships between clients and family members. They also reported administering therapy at a level much deeper than they could in typical clinical settings. What contributed to this more in-depth therapy is both learning evidenced based aphasia treatments and the increased amount of time that the client participates in those therapy tasks. Further research should include an increased number of sites and clinicians to obtain a larger sample of perspectives so that clinician experiences can be more easily generalized to other newly developing ICAPs. For future considerations, ICAP clinicians may begin to think about how to overcome the challenges inherent in delivering the programs so that the rewards are reaped by more clinicians and participants.

5.0 Chapter Five: "All in the same boat": Insights from participants and families after taking part in an intensive comprehensive aphasia program (ICAP)

Study Four (Chapter Five) aimed to understand the experiences of the participants and the family members who took part in the ICAP. Interviews took place immediately following participation in the program and only first-time participants were included. The interviews were transcribed and coded for themes. The chapter will be submitted to the International Journal of Communication and Language Disorders.

5.1 Abstract

Background: Intensive comprehensive aphasia programs (ICAPs) have increased in the US and abroad in recent years. Outcomes from ICAPs have demonstrated behavioral improvements for most participants. However, little is known about the experience of the ICAP from the perspective of the participants and their family members.

Objective: The aim of this paper was to explore, through qualitative interviews, the experiences of participants with aphasia and their family members who took part in an ICAP.

Methods: We used a semi-structured interview to ask participants (n=12) and family members (n=10) about their personal experiences of recently completed an ICAP. Nine persons with aphasia were interviewed with their family members and three chose to take part in the interview alone. Including family members, there were a total of 22 interviewees. The Framework Analysis method was used to identify themes representing their experiences.

Results: Transcripts were categorized into themes relating to intensity of the treatment, types of improvements they experienced, and relationships they were able to form. An overarching theme pertaining to a therapeutic milieu emerged. Participants and family members discussed how the physical and social environment were important factors that contributed to create the therapeutic environment. The therapeutic environment led to changes in language, conversation, physical abilities, and psychosocial health.

Conclusions: Participants with aphasia and family members describe positive experiences and detailed changes after taking part in an ICAP. They describe how the therapeutic milieu of the ICAP was interwoven with the intensive therapy to create a "package" of therapy that led to improved outcomes.

5.2 INTRODUCTION

Little information is available about what persons with aphasia think about the treatments they receive. As recipients and primary stakeholders of aphasia treatments, their thoughts and opinions are important to guide development of outcome measures and implementation of treatment approaches. Fratalli suggests that outcome measures should include satisfaction as one dimension, as compliance with treatments could be dependent on a person's satisfaction with that treatment.[152] Information about what is an important priority for person with aphasia and family members may help refine treatments, programs, and outcome measures to meet their needs.[153] There is currently, no research on perspectives from persons with aphasia and family members regarding their participation in an Intensive Comprehensive Aphasia Program (ICAP).

Given the increase in the number of intensive comprehensive aphasia programs (ICAPs) in the US and internationally, there is a need to understand the dynamics of how a rehabilitation approach like an ICAP may differ from other treatment approaches. Rose and colleagues defined an ICAP as a program that provides at least three hours of therapy a day for at least two weeks to a cohort of participants who begin and end the program at the same time.[50] The comprehensive component means that ICAPs address impairment and life participation goals in both individual and group sessions. Additionally, education for participants and family members is another important component of an ICAP. Consistent with Donabedian's quality control model that stresses the importance of understanding how changes in structure and process impact outcomes,[25,26] Babbitt and colleagues analyzed the structure, process, and outcomes of one ICAP.[22,23,112] They described how the structure and process of that ICAP differed from that of traditional therapy, with resulting outcomes that included significant changes from pre- to post-treatment on various behavioral measures. Similarly, several other studies from established clinical and research ICAPs have found that most participants make progress in at least one area when assessed with both impairment and patient-reported outcome measures.[43,57,73,74,112,150]

While we know that there are significant quantitative gains following participation in an ICAP occur, we do not know what the stakeholders think about these types of treatment programs. Qualitative interviews are an important methodology to gain information and understand those perspectives. Recently, clinicians who worked in an ICAP were interviewed as stakeholders. As providers of the treatment, they are essential to the success of an ICAP.[75] Clinicians felt there were very different aspects of ICAP service provision as compared to

the typical treatment settings in out-patient or day rehabilitation in terms of providing more in-depth treatment, seeing more progress in the participants, learning from other clinicians, and seeing stronger relationships between persons with aphasia. Unfavorable comments about working in an ICAP mostly regarded the amount of time needed for preparing therapy material and thinking about next steps for treatment. Clinicians also indicated that they felt disappointment when returning to their previous therapy environment due to factors such as insurance restrictions on the amount of therapy, less support from family members, and limited time for education on evidence-based practices. The most recent Cochrane review of speech-language therapy for aphasia found that in trials comparing intensive to non-intensive therapy there was a greater drop-out rate for the higher intensity treatments.[46] Given the negligible drop-out rate reported in ICAPs, it is, again, important to know what the participants and family member think about this type of intensive treatment and why there may be a smaller drop-out rate than other intensive studies reported in the Cochrane review.[43,55-57,73,112,150,151]

We do not know what participants think about ICAPs as a particular form of treatment, however, there are some reports of their experiences of aphasia treatment. One study analyzed unsolicited comments about their participants' satisfaction/dissatisfaction with their health care as part of their overall descriptions of their experiences of aphasia after a stroke. These themes included: forming relationships, manner and methods of service delivery, information/ communication/ knowledge, structure and relevance of therapy, organizational management, individual support, and positivity and improvement.[154] Samples of comments that indicated satisfaction with their treatment related to receiving information and treatment was tailored to their individual needs, being treated as an equal and intelligent person, and receiving positive feedback and hope. Dissatisfaction was related situations such as being dismissed by health care professionals, not receiving enough family education or accessible information, or feeling that they had no control over discharge plans. Using mixed-methods of semi-structured interviews and self-report measures of health-related quality of life (HRQL), Corsten and colleagues found a person's sense of self changed following a biographic-narrative and group interventions. Following narrative-based treatment, participants identified improved HRQL and mood, specifically in the constructs of psychosocial health and language abilities.[155] Wenke and colleagues solicited feedback of participants following an intensive sub-acute protocol, which was not an intensive comprehensive program.[156] The responses indicated that the participants thought the

therapy was helpful, enjoyed the social aspect, noted the quality of the staff, reported increased confidence, and saw improvements in themselves.

Family members and caregivers are also key stakeholders in treatments for persons with aphasia. Grawburg and others reviewed the literature regarding the impact of aphasia on family members and summarized the results according to the World Health Organization's International Classification of Functioning and Disability. They noted that the lasting effects of aphasia contributed to third-party disability for the family members.[157,158] These effects on family caregivers can be seen in direct out-of-pocket costs, lost wages and productivity, and can impact physical and emotional health.[159,160] Interviews revealed changed interpersonal relationships, loss of autonomy, a need for respite and support, and a need to process their own grief.[6,54,161-163] Given the impact aphasia has on family members, it is important to gain insight into family members' perceptions of an ICAP as well because ICAPS typically include the family member and, to some extent, address their needs too. However, there is sparse information from families and caregivers about their perceptions of health care interventions. One study did ask for feedback from family members regarding an intensive intervention. Mackenzie's study asked family members what they thought the benefits were of the treatment for the person with aphasia.[56] They noted improved communication, increased attempts to communicate and increased confidence in communicating. Other benefits mentioned in addition to therapy-related changes were having a daily routine, meeting others with similar problems, receiving treatment outside of a medical setting, demonstrating a happier frame of mind, and increased alertness. Three out of five family members reported the four-week protocol was not long enough.[56] Wenke et al also asked caregivers for feedback following the intensive sub-acute treatment study and caregivers reported their family member with aphasia showed increased confidence, positive changes, they noted the quality of the staff, and felt the treatment "could go longer."[156]

While research regarding behavioral outcomes from ICAPs is emerging, the perspectives of the primary stakeholders, the person with aphasia and their family member is still lacking. It is important to know how they describe their experience. As health care moves towards using patient reported outcomes and satisfaction with care as metrics for standards of care, it is essential to examine their experiences.[164] The aim of this paper is to describe the experiences of the person with aphasia and the family member after taking part in an intensive comprehensive aphasia program.

5.3 METHODS

This study utilizes a phenomenological approach which "describes the meaning for several individuals of their lived experiences of a concept or a phenomenon."[59,60] Through semi-structured interviews, participants were guided in the discussion, but could share their thoughts without constraining ideas. The phenomenological approach seeks to understand what persons with aphasia and family members experience as consumers of this different type of therapy model.

5.3.1 Program

This self-pay ICAP provided six hours of treatment, five days a week for four weeks to a cohort of ten participants with aphasia. The total cost of treatment is based on the hospital's standard hourly rate. Data on participant's own costs of living away from home (per-diem miscellaneous costs and housing costs) have not been collected. During the six hours of treatment each day, participants received a variety of evidence-based treatments which included: two hours of individual treatment, constraint-induced aphasia treatment (in pairs), a reading/writing session, computer session and conversation group. The ICAP was physically located in an office building and while some participants were local, others had come with their families form other regions of the United States and internationally. A more detailed description of the program can be found in Babbitt et al's 2015 article.[112]

5.3.2 Participants

Participants were recruited from two cohorts who completed the ICAP at the same facility. It was their decision whether to include a family member in the interview. Nine study participants said they preferred a family member to be included in the interview. No family members were interviewed without the participant. Of the 20 ICAP participants, 17 attended for the first time and 12 of these were available and agreed to take part in the study. Five ICAP participants did not take part in the study for a variety of reasons: non-English speaking and an interpreter was not available, did not want to take part in the study, or were leaving town right after the program and did not have access to Skype. Nine of the twelve study participants were from out of town. Our preference was to conduct the interviews face-to-face and in person due to difficulties using supported conversation via a Skype or phone call. However, one person participated in a Skype call with his wife and another person with aphasia was interviewed on the phone by himself. In the Skype call, the wife wrote key words for the participant to point to if needed for clarification. He also had a printed version of the questions, his daily schedule, and pictures of the other participants. Visual supports

were not needed for the phone call, as the person was diagnosed with mild anomia and had good comprehension. One participant was interviewed with both parents who accompanied her during the program. The number of participants is consistent with the number suggested for phenomenological research (i.e., 5-25).[59]

The participants who agreed to be interviewed were representative of all the other first-time participants who have taken part in the program (n=79). There was a range of severity, type of aphasia, and time post onset. However, the 12 interviewees from this study appear to be slightly older (mean age = 64.3 years) as compared to the 79 first time participants (see Table 5.1). All 22 participants (persons with aphasia and family members) signed approved consent forms from the Institutional Review Board of Northwestern University and The University of Queensland. Participants P01 – P05 were in the first ICAP and participants P06 – P12 were in the second ICAP. Table 5.2 shows the similarities of the 12 interviewees to the overall total number of participants and independent samples t-test and chi2 show the groups are very similar except for age and type of aphasia. Demographic information about the participants was collected from their application forms. Demographic data was not collected on the family members because they were the participant's support person in the interview, not an independent source of data or participant. Lacking information about the family members does not impact the analysis of the data. There were no drop-outs over the two cohorts of this ICAP. Only a few participants dropped-out over all of the cohorts since the program started and those were related to medical issues during the last week of the program.

Table 5.1. Demographics of 12 interviewees

ID	Time in ICAP	Age	Gender	MPO	Occupation	Aphasia Type	WAB AQ	AQ Change	Family Member Present
P01	SP14	56	M	14	Business	F	33	8	Wife
P02	SP14	77	M	14	Retired	F	55.5	-2	Daughter/ Son (phone)
P03	SP14	48	F	20	Health Care	NF	48	6.3	Parents
P04	SP14	62	M	4	Retired	F	85.7	8.9	None
P05	SP14	67	M	32	Retired	NF	33.4	5.6	Wife
P06	FA14	75	M	16	Education Administration	NF	31.7	13.8	Wife
P07	FA14	58	F	17	Self-employed	NF	23.6	5.1	Husband
P08	FA14	44	M	45	Engineer	NF	44.5	8.1	Mother
P09	FA14	66	M	9	Health Care Administration	F	27	.2	Wife
P10	FA14	73	F	3	Education	F	83.4	7.6	None
P11	FA14	74	M	5	Business	NF	74	11	Wife (skype)
P12	FA14	72	M	5	Self-employed	F	78.3	9.8	None (phone)

Key: SP14 = Spring 2014; FA14 = Fall 2014; M = male; F = female; MPO = Months Post Onset; NF = Non-fluent; FL= Fluent; WAB-R AQ = Western Aphasia Battery – Revised Aphasia Quotient

Table 5.2. Comparison of 12 interviewees and 79 other ICAP first-time participants' demographic characteristics

	Interviewees n = 12			**Other ICAP Participants n = 79**			**Significant Difference**
	M	*SD*	*Range*	*M*	*SD*	*Range*	*Independent samples t-test*
Age in Years	64.3	(10.9)	44 – 77	53.8	(16.4)	18 – 86	0.02
Months Post Onset	15.3	(12.5)	3 – 45	16.3	(18.6)	3 – 120	0.43
WAB-R AQ /100	51.4	(23.1)	23.6 – 85.7	49.2	(22.5)	7.0 – 91.4	0.38
WAB-R AQ Difference Score	6.9	(4.4)	-2.0 – 13.8	7.4	(5.8)	-9.6 – 24.0	0.38
BNT	17.7	(20.8)	0 – 55	16.8	(18.9)	0 – 56	0.45
CCRSA	26.9	(8.0)	14 – 40	27.2	(6.0)	12 – 39	0.44
		n			*n*		
Gender	M	9	75%	M	55	70%	
	F	3	25%	F	24	30%	
Aphasia Type	NF	6	50%	NF	57	72%	
	FL	6	50%	FL	22	28%	

Key: *M* = Mean; *SD* = Standard Deviation; WAB-R AQ = Western Aphasia Battery – Revised Aphasia Quotient; BNT = Boston Naming Test; CCRSA = Communication Confidence Rating Scale for Aphasia; *n* = number of participants; M = male; F = female; NF = Non-fluent; FL= Fluent

5.3.3 Data collection

Participants were interviewed at the end of the last day of the program or within two days following the end of the program. The person with aphasia was asked if they wanted to be interviewed alone or with a family member. The family member was given the opportunity to be interviewed alone if both parties agreed but no one took up this option. Participants were interviewed at a location of their choosing. The interviews ranged from 48 to 87 minutes

(mean = 65.5, SD = 12.6). The interviews were digitally audio and video recorded and transcribed by the first author or trained volunteer. The first author, who conducted the interviews, was an experienced speech-language pathologist (>15 years) who was competent in the techniques of supported conversation for adults with aphasia to be able to maximize the communicative participation of persons with aphasia in the interviews. The interviewer had experience working as a clinician in the ICAP; however, she was not involved in these two cohorts and was not privy to evaluations or discussions regarding any participants. Aphasia-friendly adaptations were incorporated throughout the interview process such as using paper and pen to draw and write key words and picture supports.[165] Picture rating scales were available and participants used printed materials from the program including schedules and photographs of others. There was no particular order that questions were asked, but the interviewer used a question guide to follow during the semi-structured interviews (see Table 5.3). Each question was typed on a separate piece of paper which allowed the participant and clinician to write or draw concepts or ideas related to that question. Unclear responses from the participants were verified by repeating or writing down the information for clarification. At the beginning of the interview, the interviewer stated that she would direct the question first to the person with aphasia and then to the family member to reduce the possibility of the family member responding for the person with aphasia. The questions were used only as a guide and participants had the flexibility to talk about what was important to them. Participants were prompted with the question “Anything else?” to ensure they had completely answered the question before asking the family member for a response. After early interviews in which participants and family members consistently brought up relationships, the following question was added, “What did you think about working with the other participants?” The question guide was printed and given to or emailed to the participant and family member prior to the interview to allow them time to think about the questions and their responses.

Table 5.3. Question guide for interviews

Tell me about your experience with RIC's Intensive Comprehensive Aphasia Program.
Why did you want to take part in an intensive comprehensive aphasia program?
What were your expectations before you started the Intensive Comprehensive Aphasia Program?
What was it like for you during the four weeks of the program?
Now that the four weeks has ended, what do you think at this point?
What stands out the most about your experience in this intensive aphasia program? Are there other things?
What things have changed for you as a result of participating in an intensive aphasia program?
What things have changed for your family member as a result of participating in an intensive aphasia program?
If we revised/changed the program, what would you like to keep?
What would you like to change about the program?
Is there anything else you want to talk about/discuss?
Do you think we have covered/talked about everything?

5.3.4 Analysis

The interviews were reviewed and coded using Ritchie and Spencer's approach to framework analysis.[61,166] Framework analysis provides a systematic, orderly analysis of qualitative data, while allowing for flexibility to revise throughout the process. The first author and two independent reviewers coded the interviews. First, the reviewers familiarized themselves with the data by transcribing the interviews, watching the video recordings, reading the transcript several times, and writing down their thoughts related to the content. Next, the content of each interview was divided into sections in which one complete thought or idea comprised a section. These ideas were each labeled with the participant's ID and numbered sequentially. A key word or phrase that represented the idea was highlighted. To develop consistency when coding, the reviewers all coded one interview, and then as a group, discussed each idea to determine the code for that idea. Group consensus was reached after discussing differing views on what each idea meant. An index of the codes was developed and each comment of the second interview was then matched to a code in the index of codes. This index was refined after review of several transcripts to include additional codes as needed. After coding four interviews, no new codes were identified,

indicating that the codes covered the breadth of ideas from the interviews. See Appendices H and I for the Index of Codes that was developed and an example of a completely coded interview transcription. The remaining transcripts were then coded as per this index.

5.3.5 Rigor

Graneheim and Lundman describe measures for ensuring the rigor and trustworthiness of qualitative analysis.[141] Credibility for this study is highlighted by the inclusion of a range of ages, months post-onset, and severity levels of persons with aphasia in the group of interviewees. Additionally, interviewing participants from two consecutive ICAPs allowed for any differences in the dynamics of the different cohorts. Discrepancies among the reviewers in defining and assigning codes to the comments were discussed and consensus was reached which leads to greater credibility. Peer debriefing which was obtained by consultation and confirmation with experienced researchers (the second and third authors) also enhances credibility.[142] Transferability may be limited as the interviews focused on participants from only one ICAP. A larger scale study would be necessary to understand the experiences of persons with aphasia and families from other programs, which may differ in their staffing, programming, and implementation of the aphasia treatment protocols. However, this study can give insight into some of the differences between intensive comprehensive treatment programs and other therapy settings. To enable reflexivity and an audit trail, the first author has kept a journal throughout the interviewing and coding process. Participants and family members were not asked to review the interviews or themes once the analysis was completed. This could be considered a limitation of the study; however, reviewing the information with the participant should occur in person with and we not able to provide that opportunity. Future studies should consider extensive member checking of the analysis.

5.4 RESULTS

Persons with aphasia and their family members described three main themes after taking part in an intensive comprehensive aphasia program. Their comments revolved around the process of treatment, the improvements they saw taking place and their relationships with other participants and family members. While most of the reported experiences during the program were positive, negative comments by participants and family members are also included in this paper. Quotes have been modified for clarity by removing filler words like “um”, repeated words, and words that do not add meaning to the quote. See Table 5.4 for an overview of the themes and sub-themes.

Table 5.4. Themes and sub-themes described by participants and family members

Therapeutic Milieu		
Treatment	Length / intensity	
	Speech-language pathologist	
	Comparison to previous therapies	
	Reflection / evaluation	
Outcomes	Language and conversation	
	Psychosocial	
	Physical and ADLs	
Relationships	***Participants***	***Family Members***
	Meeting other persons with aphasia	Supporting each other
	Forming bonds & supporting each other	Meeting other family
	Social interactions	Social interactions
	Family supporting person with aphasia	

5.4.1 Treatment: "Challenge… head… helped your brain (P03 04)"

Several sub-themes related to the larger theme of treatment: the intensity or length of the program, the expertise of the speech-language pathologists, reflections on expectations, and differences with previous treatment. As was expected, all participants talked about the intensity and the length of the program. In terms of intensity, about half of the participants reported being tired at the end of the day or suggested time for a mid-day nap. Words that were used to describe the treatment included, "intense," hard," "strenuous," and "a challenge." Two participants snapped their fingers quickly to indicate the pace of therapy. One said "grueling (P01 10)" and the other said "happening (P03 34)." Other participants did not report being tired or didn't think it was too much work when asked. Participant P04 (54) described the therapy as "accelerated." P10 noted that there was a lot of repetition and practice which was good (70, 74). Related to the length of the program (4 weeks), half of the participants would have liked the program to be longer, several indicated it was fine as is, and one person suggested a break in the middle of the four weeks. Even though many people mentioned how hard and challenging it was, only one person suggested a reduced schedule with slightly fewer hours per day and slightly less days per week (P11). P03 indicated that the concentrated time allowed her to become closer to the others in the short

time. One participant, P09, who had a difficult time at the beginning of the program. His wife described how long it took him to adjust, “I mean he hated it. He was so upset for at least the first week…. But about this weekend… he actually felt like he was understanding everything and it was clear and he was happy… He’s had several other short periods where he’s… felt like maybe the program was helping (P09 07).” This participant with a fluent aphasia described what was difficult for him, “There were all kinds of stuff going on… They were [I was] all over the place. Because they [I] would be going to one place one time and then other day another time. It was like here we go again (P09 22).” He also described how he changed over time and adapted *to* the computer sessions. “They [I] couldn’t figure out what they were [I was] supposed to be doing. But after a while they [I] realized that they [I] wanted this stuff… they [I] understood that this stuff, which was encurling [encouraging?], they were [I was] beginning to say ‘yeah’ this stuff is good (20).” In these quotes, he used “they” but it was interpreted to mean that he was referring to himself, therefore, the implied meaning is included in parentheses. Even though he initially did not want to take part in the program, he could identify positive factors and things he did like about the program.

Many positive comments were made about the speech-language pathologists in the program. The participants and families reported that the therapists were “challenging,” “motivating,” “giving,” “patient,” “supportive,” “encouraging,” “hard-working,” and “expert.” A few negative comments were made about their experiences with previous therapists in other programs. One family member said the clinician was always late which cut into therapy time and another one said the clinician never had time to talk with her about her husband’s treatment. One participant noted that he liked working with the different therapists in the ICAP program because “I like change on pretty much everything I do so that was nice (P04 26).” One family member felt she had a “whole network of people trying to help [her husband]” and that “an important component of this program is the interaction between the family and also the staff (P05 53).” Several participants relayed strategies their therapists worked on with them, noted that the therapist individualized their treatment or engaged everyone in the conversation group.

Participants and family members also identified how, apart from the intensity, the therapy activities were different from previous therapy. P02’s wife described it as an “integrated approach… above the standard approach… mixing it up… going a lot quicker ways to receive the benefits and retraining your brain (67).” P04 remarked that he wanted more “dynamic” therapy and prior to attending this ICAP, he “couldn’t see anyone else that could

help me like I wanted (10).” P02’s daughter talked about the limited therapy her father had received with Medicare, and noted that in the ICAP program “the focus was more on whole language (05).” About half of the participants preferred individual treatment over the other sessions. Others enjoyed all sessions with no preferences. A few remarked that they didn’t particularly like the paired session if they didn’t “mesh” with their partner. When one participant had a good partner, she described it as “we just had a good time doing that… we had a good laugh (P10 54).” P09, who did not enjoy the program at first, indicated that he liked working with his individual therapist and gave this component a 9/10 on a rating scale.

Reflective comments related to why participants wanted to take part in the program, expectations of the program, and how the program helped them. Most of the participants and family members did not express explicit expectations, but instead talked about “wanting to improve,” “wanted to see if the program would help,” “hoping to speak better,” “open to see what would happen,” “looking for something new, more dynamic,” or “thought I could be better.” Two family members stated specific expectations of improved words, confidence, and communication (P01, P06). One participant, P11, indicated he had no expectations at the beginning but thought he would have been better by the end of the program. One family member said he had no expectations, but did have a worry that nothing would happen (P07). While participants and families didn’t necessarily state specific expectations, several said that the program exceeded their expectations and felt it was the “best thing to ever happen,” had “never seen a program like this and learned what therapy is,” felt the therapy provided was “more in depth.” Two participants, P04 and P10, noted that the program helped them because they didn’t know what to do next or didn’t know what they would have done without the program. P10 stated the program was like a “…life boat. It was something you could do to help yourself (42).” P05’s wife used the metaphor of the program being a “stepping stone (10)” and “from this experience I know where we go from here (46).” Families also felt supported through the family programming that provided additional resources.

Comments were made regarding how the participant and family member saw differences between the intensive program and previous therapies. Some mentioned that they had not had group therapy before, others noted that they had, but only once a week and they would like more. A few remarked that there was no sense of community or getting to know each other in their previous therapies. A few participants mentioned that technology was new to them and increased their participation in communication activities. They reported now using their phones or tablets to support their own communication in conversations. Some had not

used social media since their stroke and noted that goals were developed to support their engagement in different types of media interactions. Being able to communicate with friends again using social media had a very positive effect for some participants (P03, P07, P08). Other participants were already using technology (P06) or were frustrated with technology even though their families wanted them to use a phone or tablet (P02).

Participants were asked what would be next after the program ended. Many said they would continue with speech therapy and practicing their home exercise program. A few indicated would be continuing with physical therapy or exercise. Three family members said that they planned to bring the treatment recommendations to their regular speech therapist to be able to continue similar treatments. Several said that they would be "getting on with life in general (P09 41)," or pursuing activities like contacting friends and family by social media, emailing and texting.

5.4.2 Outcomes: "Every day it was… little bit more, little bit more" (P01 42)

Many participants and family members reported general positive improvements such as "I think he made great improvements (P11, 23)". Others reported more specific progress which fell into three sub-themes related to language and conversation, psychosocial health, and physical functioning. When participants indicated changes, they were asked if they could give examples. Speech improvements were described as getting more words and different words out. P08 stated, "Oh yes, lots more. Lots more. Good. Specific things (55)." He reported being able to place his coffee order when asked to give an example of improved speech. His mother reported increased length of utterances, "He's talking more. I can see that he's talking more. He would … talk only one word at a time (P08, 61)." Family members noted that they could have better conversations with the participant. P11's wife stated, "we can discuss things now (26)." In terms of other language improvements, writing was mentioned with improvements noted in tasks like writing one's name, writing more complex sentences or being able to complete crossword puzzles. Reading improvements were not mentioned by many participants. One participant mentioned that he did not see improvements in reading that were indicated in the post-treatment evaluation and he felt his reading was fine. Comments related to change also reflected thoughts about not seeing large improvements, seeing variable and fluctuating progress, or not seeing the progress they have made. One participant's husband remarked about his wife's overall improvements, "It may not feel like a huge jump but I think it can build (P07 66)." Another participant didn't agree with his wife's observations about his speech improvements and

stated, “I’ve noticed the change in a particular instance but it disappears (P11 24).” Another older participant felt he had limited time to make progress (P06 57).

Participants and family members remarked about changes in psychosocial adjustment. For the persons with aphasia, improvements in confidence and general mood were noted. More than half of the participants reported that they had more confidence either in general or in specific situations such as talking to other people in a restaurant. A few participants reported that they were apprehensive before attending the program and one participant did not want to be there at all (P09). Other participants commented on and reported more positive mood of those participants after being in the program for a period of time. Family members also noted self-reported changes, as one noted that she felt “much less stressed (P11, 73).” Another one stated that she “can now step back a little bit, he’s capable of more than I thought. My whole world has changed (P05 48).” In relation to her husband taking the train daily to the program, one spouse said, “He can be more independent and I don’t have to be so afraid (P01 67).” One person with aphasia remarked that he and his wife were “more tolerant of each other” and that his wife was “more tolerant of [his speech patterns] (P04, 41).”

Interestingly, several participants reported participation improvements in other areas including physical progress or general tasks related to activities of daily living. Stamina was mentioned by the wife of one participant; however, the participant himself didn’t notice improved stamina or less fatigue (P11, 19). The participant who took the train daily began walking without his cane and his wife noted, “so he started making a lot of physical progress, too (P01 59).” One participant reported that “I can now dress myself (P10, 37)” commenting specifically about putting on shoes and donning a bra. She also mentioned that “I used to do all of the finances… I still have trouble with” but indicated that she was returning to her role of managing the finances (P10, 40). Others reported ordering in restaurants which hadn’t been done before (P06 22) or improved numbers and memory (P04 06).

5.4.3 Relationships: “People, people, people. But they wonderful (P06 45).”

Relationships received attention from both the participants and family members and specifically in response to the question “What stands out the most to you?” Many responded that it was the people, the opportunity to meet others with aphasia, and have social relationships that stood out to them. Overall, four sub-themes were identified for the participants: meeting others with aphasia, forming bonds and relationships, having social

interactions, and supporting each other. The participants valued the opportunity to meet others with aphasia, as about half of the participants either had never met others with aphasia or had only interacted in passing during previous therapies. There was also strong endorsement for social interactions that led to forming bonds with each other. To a lesser extent, participants made comments about helping and supporting each other. Relating to the theme of meeting others with aphasia there were many general comments: “very nice”, “very positive”, “enjoyed every person”, “very exceptional”, “people, people, people, but they were wonderful.” Several compared themselves to others; seeing different types and severities of aphasia was eye-opening, sometimes in recognition of how well they were doing and other times in recognizing what others could do in spite of their disabilities. The participants also discussed forming bonds with the other participants by noting there was a shared understanding, they could communicate with each other, and that they were sad when the program ended. The third sub-theme, social interactions, was characterized by comments about enjoying the interactions either through partner sessions, conversation group, having lunch during the program and dinner outside of the program. Comments relating to help and support of each other formed the fourth minor sub-theme under the heading of relationships. Half of the participants or their family members identified ways the participants supported each other during the program. This took the form of concern for the well-being of other participants and receiving support and motivation from being in a group of others with aphasia.

For persons with aphasia and family members, one sub-theme that appeared to be important was support from family members and having family members involved in the program. P04 reported that having his mother and brother visit him during the program gave them a better understanding of aphasia and his abilities (42, 43). Another participant (P10) felt that having the family members present during the program was important and she hadn’t experienced that in previous therapy (107). However, one participant who attended the program by himself, P12, indicated that he “didn’t want anybody… telling me doing. I have to figure it out for myself (25).” P01 indicated that he missed the support and friendships he had with his coworkers. Similar sub-themes were described by the family members and comments indicated that helping and supporting each other was most important and to a lesser extent, social interactions and meeting other family members. Negative comments from both participants and family members related to dynamics of interactions and relationships of others in the program. In particular, one family member made several critical comments during the interview and others noted in their interviews that this person was

overbearing. These types of interactions also included a wife who disregarded her husband's opinions and was not present for much of the program. This indicated that they were observant of not only their own interactions, but whether interactions of others were supportive.

Participants also noted that they saw changes in their family members as they slowed down their speech, become more patient or tolerant of mistakes, and gave more time for the person to respond. Participants also began cueing the family members to give them time, for example, by saying "shh (P07 91)." Several family members commented that they felt they learned a lot from the family education sessions at the beginning and end of the program. Three family members indicated that they would incorporate strategies of supported conversation after having the training.[167]

The family members talked about the sub-theme of meeting other family members which provided them with friendships, learning about how others made adaptations, and other resources. Several mentioned bonding with the other family members through hearing others' stories and mentioned that having a space dedicated to the family members allowed for those relationships to develop. Others wanted more opportunities for more bonding. One family was local and working so they were not part of the day-to-day schedule. They expressed a desire that there be more opportunity to engage with the other families.

5.5 Discussion

Overall, there were three main themes that the participants and family members discussed to describe their experiences with an intensive comprehensive aphasia program. Comments reflected their thoughts about treatment and intensity, progress or lack of progress, and relationships they formed. The aim of an ICAP is to provide comprehensive, intensive treatment that addresses both language and participation. Consistent with these aims, participants and family members reported not only changes in language and conversation abilities, but also increased participation, psychosocial health, and physical improvements. ICAPs also provide family education and, based on comments from family members, structured information sessions were important, but unstructured interactions were just as important to provide psychosocial support. Based on what was described by the participants and family members, it is a holistic treatment that impacts the participants and family members in multiple dimensions.

One could describe this ICAP as providing a therapeutic milieu. Merriam Webster's online dictionary defines milieu as "the physical or social setting in which people live or in which something happens or develops."[168] Barnett and Casper defined social environments which "encompass immediate physical surroundings, social relationships, and cultural milieus within which defined groups of people function and interact."[169] The theme of environment was intertwined through the three main themes in comments by participants and family members. What they described was the therapeutic milieu of the physical environment and the social environment coming together to impact a person's language and conversation, psychosocial, and physical outcomes. The physical setting was described as impacting outcomes in each of the main themes. It appears as though being in physical proximity for an extended period led to more opportunities to interact which led to improved language and conversation and psychosocial outcomes. Being in the geographical location of a large city led to people walking to/from the facility, getting out of comfort zones, and doing activities on the weekend which led to increased physical activity outside the ICAP and improved psychosocial health. Being in proximity to each other for an extended time led to activities like meeting for breakfast, dinner, or drinks. This, in turn, allowed more opportunities for talking, bonding and developing relationships. Having more social opportunities for talking may have also contributed to improved language, conversation, and psychosocial health. Being in the same physical space in the office building led to sharing stories in the family room and more opportunities for persons with aphasia to interact with each other thru out the day. Several used the metaphor of "all in the same boat" which could be interpreted as being in the same small space allowed for persons to bond, hear others' stories, or get to know others who were going through the same experiences. P09's wife commented that the family room was a place "where you got all of the stories. Just hearing their stories and realizing everybody is in the same boat (36)." One family reported that they missed those types of bonding experiences because they were working and in the suburbs (P02). Additionally, two family members noted that their family member considered the treatment as "work" (P01 P05) and that operating the program within an office space located off-site from the main hospital helped improve the participants' psychosocial outlook.

Overall, the majority of the day was spent in a social environment and in the company of others. Out of a total of seven hours, two were spent in individual treatment session, the rest were in pairs or small groups, or working independently, but in a group setting. In terms of the therapy environment, many participants reported that they enjoyed the individual sessions the most; however, they also described how they enjoyed the paired and group

sessions with others. A few specifically indicated they did not like the paired therapy as much when they didn't "mesh" with the other person. Conversation group was an opportunity where they had fun and got to know each other better. They also described the fast-paced therapy environment, and how they felt motivated and supported each other. The types of therapy activities allowed for and encouraged interactions between the participants. One person commented that the therapists were skilled at being able to incorporate everyone in the discussion. Even P09, who had a hard time adjusting to the program, said about conversation group, "These guys are funny, it's everybody. That's like 'well, what do you think?'" The social environment not only impacted their language and conversation outcomes, but impacted their psychosocial health as reported in the interviews. Participants and family members noted that the length and intensity of the program was what led to the bonding and allowed relationships to develop. Many also wanted the therapy to continue, possibly for another week or two.

One might think that with the monetary and time investment in a self-pay ICAP, participants and family members would likely be more motivated to report better outcomes. Only a few intensive research studies have reported feedback from participants and family members.[56,156] While these two treatment studies did not provide all aspects of the definition of intensive and comprehensive aphasia programs, one study provided two hours of daily treatment for 11 weeks (e.g., individual session and computer or group or SLP assistant session) and the other study provided five hours of daily treatment for four weeks (e.g., individual and group sessions). Both provided individualized treatments; however, there was no mention of family education or involvement. These studies obtained feedback from participants and family members through questionnaires. Persons with aphasia in Wenke's study reported changes in language, conversation, and psychosocial aspects. They thought therapy was helpful and saw improvements, they enjoyed the social aspect and noted increased confidence. Families also reported similar thoughts and additionally, made comments that the therapy could have been longer.[156] In Mackenzie's study, families reported almost the exact same ideas regarding language and conversation as we found: improved communication, more willingness to attempt communication, increased confidence, and initiation of more conversation.[56] They also commented on improvements in psychosocial health and identified their family member had a happier frame of mind and increased alertness. Meeting others with similar problems was another positive factor as a result of taking part in the study. These family members also noted that the physical environment was important as it provided the opportunity to travel to the location as part of

a daily routine and that the location was outside of a medical setting. Again, family members reported the four-week protocol was not long enough. Tomkins et al interviewed persons with aphasia and family members to identify what contributes to overall satisfaction with clinical aphasia therapy.[154] The authors found that the structure of therapy and language improvements were important, but additional factors that contributed to psychosocial health were also important: relationships, support and positivity.

If one compares feedback from this self-pay ICAP and the two studies of publicly funded intensive treatment, we see that similar comments were made across both groups. One area which was expressed in the interviews following the ICAP was about the aspects of the treatment the person enjoyed, but this was not addressed in the questionnaires of the other studies. We found that participants enjoyed the individual therapy sessions the most, but many also said they appreciated all of the sessions. Other themes that arose that were not reported by the other studies related to the relationships and the comments about the support from both the participants and family members that occurred in this ICAP. The ICAP provides more opportunity for relationships to develop and grow stronger due to being in close proximity for an extended period of time with opportunities to engage outside of the ICAP. Persons attending the ICAP have allocated a 4-week hiatus from their usual routine. The participants in the two other research studies were from the local area and went from home to therapy as part of their normal routines. One person dropped-out of Wenke's study because it interfered with his daily activities. Another theme that was not expressed in the other studies was that of improved stamina or physical abilities from walking in the city and in the office building during the day. While many of the themes were similar, especially related to the treatment, we found that participants and family members commented on additional outcomes from the ICAP that were important to them.

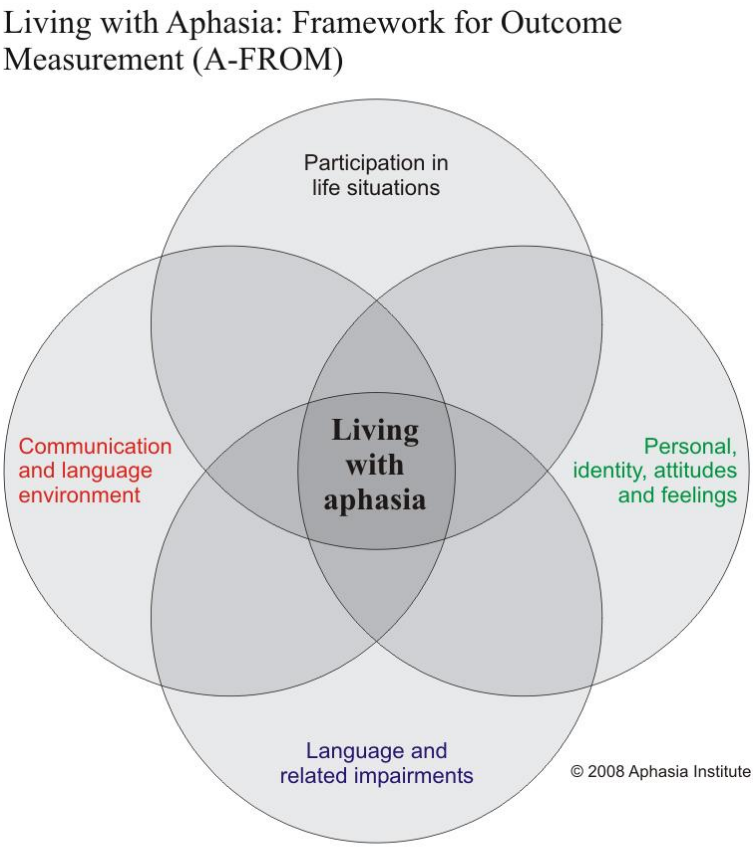
The themes we found in our study align closely with what was reported in previous research settings and contexts regarding participant and family perspectives.[56,156] These studies used questionnaires to gain feedback from persons with aphasia and/or their family members. The qualitative interviews we conducted allowed the interviewer to probe responses and allowed the participants and family members to reflect more on their experiences in the ICAP. The interviews allowed us to develop the concept of therapeutic milieu and how it was comprised of interactions of the intensive therapy, the social and the physical environments. We found specific examples of how participants and family members made changes and improvements which also reflected changes on language and participation measure.

It is interesting to compare the perceptions of clinicians who are also significant stakeholders in an ICAP to those of the participants with aphasia and their family members. The themes were closely aligned.[75] Comments from the clinicians indicated ICAPs provide a different kind of therapy as compared to typical treatment settings in out-patient or day rehabilitation. One clinician described the ICAP environment as "empowering… supportive… people [came] out of their shells… could see their confidence growing." Positive comments reflected that clinicians felt they were providing more in-depth treatment, seeing more progress, learning from other clinicians, and seeing stronger relationships between participants and family members. Similar comments came from the interviews with participants and family members – receiving more in-depth treatment, seeing positive gains, learning from each other, and developing stronger relationships with each other. Clinicians also commented on having stronger bonds with the participants and family members in this ICAP; whereas participants and families commented more on the skill of the therapists or made comparisons about their previous experiences with clinicians regarding the number of interactions with the therapists. Clinicians indicated that the relationships they formed with the participants were an important part of working in an ICAP. The participants and families seemed to view interactions with others who also had aphasia or were "in the same boat" as important outcomes. Perhaps because they had previous relationships with clinicians, but no relationships with others with aphasia, participants considered that there was more to gain from those relationships. A vast literature has explored the importance of social support systems in recovery from aphasia and stroke for both the person with aphasia and family members.[4,49,65,170-175] These studies have found that social support systems are an important mechanism for coping during recovery from stroke and aphasia. It appears as though this ICAP provided the opportunity for all stakeholders to develop relationships that were important to them.

An ICAP is based on concepts of intensiveness and comprehensiveness. One can examine how outcomes from an ICAP fit into the context of a comprehensive model that provides guidelines for measuring outcomes and how those outcomes impact a person living with aphasia. The Living with Aphasia: Framework for Outcome Measurement (A-FROM) model visualizes the interactions of different areas of a person's life and how those interactions contribute to living successfully with aphasia.[22,23] The model is based on the WHO-ICF and diagrammatically represents how living with aphasia encompasses more than just the language deficits (see Fig. 5.1).[47] The different representations of a person's life include: 1)

the communication and language environment the person engages in, 2) the language impairments the person has, 3) personal factors inherent to the person, and 4) participation in life activities.[22] In terms of the communication and language environment, for the four weeks of the program, participants are engaged in a language rich environment with many opportunities for social interactions. Participants and family members described learning new strategies which would enhance interactions between each other, specifically more patience and more tolerance was noted. Participants learned strategies to support their own communication in conversations with others that can be used at home. Family members' understanding of the participants' aphasia, different types of aphasia, and supporting conversation for the participant improved. Regarding language impairments, we had expected and did see numerous comments about language and conversation improvements. However, what was unexpected were comments related to personal factors inherent to the person with aphasia. These factors included: increased confidence, increased attempts to talk and engage, and reduced feelings of stress and anxiety. Changes in communicative activities were noted as comments included talking to strangers, answering the telephone, conversing with friends, attempting crossword puzzles, ordering at a coffee shop and using public transportation independently. Using the A-FROM model to describe the experiences after taking part in the ICAP demonstrates that this therapeutic environment had wide-reaching impact on participants and family members.

Figure 5.1 Living with Aphasia: Framework for Outcome Measurement (A-FROM) model



Kagan, A., Simmons-Mackie, N., Rowland, A., Huijbregts, M., Shumway, E., McEwen, S., Threats, T., & Sharp, S., (2007). Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology,* 22 (3), 258-280.

5.5.1 Limitations

Of the participants who took part in the interviews, only one participant expressed significant dissatisfaction with the program and took an extended time to adjust to the schedule. It is unknown whether participants who were not interviewed were dissatisfied with the treatment or the program. Another limitation is that the first author conducted the interviews, and although she did not work in the programs with the participants involved in this study, she has worked as a clinician with other ICAP cohorts. This could have led to a bias towards more positive questions and interpretation of responses or lack of follow up questions for clarification due to “insider knowledge” about the workings of the program. To help reduce bias, two independent people not associated with the program coded the data. There is also the possibility that the participants and family members wanted to please the interviewer because they knew the interviewer was involved with the program; however, the interviewer only interacted with the participants at the very beginning of the program and at the end when the interviews were conducted. These results may not generalize to other ICAPs with

different number of participants, hours of treatment, therapeutic approaches, or staff experience. A final limitation is that the participants self-selected to attend the program. Therefore, the participants likely had a positive perception about an ICAP before treatment The one exception was the participant who initially did not want to be at the program. However, the studies by Wenke and Mackenzie also found similar positive feedback, indicating that persons who consent to research or commit to a therapy program, regardless of whether or not they self-pay, may have a more positive view of therapy.[56,156]

5.5.2 Clinical implications

Overall, the comments from participants and family members were positive in describing the gains in language and conversation and the relationships that were formed. To provide services that maximally benefit the stakeholders, clinicians and organizations may want to look at which structures and processes of an ICAP can be implemented in a clinical setting. A setting may be able to better train clinicians in evidence-based practices or modify waiting rooms to allow for more interactions between persons with aphasia. Participants and family members also described some negative factors. Fatigue was the most noted comment, as adjusting to the day/week long treatment was difficult for some participants. Given the comments about the length of the day and intensity of the treatment leading to fatigue, an ICAP may not be appropriate for every person with aphasia. This type of program may also not be for every clinician, as there were challenging aspects regarding working in an ICAP. For many, though, the benefits outweighed the negatives. However, comments from the participants and family members about the lack of meeting other people with aphasia and lack of support for family members highlighted discrepancies between the ICAP and previous therapy situations. These integral features of the ICAP need to be incorporated into usual care.

5.6 CONCLUSION

Results from this qualitative analysis suggest that the structure and processes of this ICAP create a unique therapeutic milieu, which includes the social and the physical environment. In the case of this ICAP, participants and family members described how all aspects of the program, the close proximity in physical space over an extended period of time *and* intensive therapy led to language gains and allowed for relationships to happen. The challenge with research regarding ICAPs is the difficulty in identifying the salient or most important parts.[50] It appears that all aspects of a program are equally important and the “package” of therapy

leads to perceived changes in not only language but psychosocial health and physical function.

6.0 Chapter Six: Conclusion

This thesis set out to examine the outcomes of an ICAP for persons with aphasia. The ICAP investigated in this thesis provided six hours of treatment per day, five days per week, for four weeks for a total of 120 hours. The dose and intensity of this ICAP is vastly different from other out-patient or day rehabilitation treatment settings in the same hospital (typically ranging from two to three hours per week). Using a mixed-method, multi-study approach as outlined by Creswell, the data were examined through multiple lenses.[176] Outcomes were examined from two different perspectives by 1) analyzing quantitative change scores from pre- to post-treatment and 2) conducting qualitative interviews with the primary stakeholders to gain an understanding about their experiences. Being able to incorporate data from the qualitative interviews gave greater meaning to the quantitative data analysis (and vice versa) and formed an overarching description of the therapeutic environment of this one ICAP. The value of a mixed-method approach has been supported by health care research in other fields. For example, Munoz-Plaza and colleagues found that examining a retrospective database of antibiotic prescription habits coupled with qualitative interviews with physicians provided richer data than using one method alone. Data from both methods then informed future practice.[177] It is contended that the combined findings of this thesis will inform future aphasia treatment approaches because it combines both the stories of the stakeholders and the quantitative statistics that measure the outcomes.

The purpose of this chapter is to summarize the findings and combine both the qualitative and quantitative sets of data to describe the structures, processes, and outcomes of this ICAP. Some limitations of the overall approach used in this thesis are provided as well as a discussion of future research needs in this area.

6.1 Outcomes from Intensive Comprehensive Aphasia Programs

While intensive treatment has been described in the literature, research studies have generally examined only one treatment at a time in randomized control trials, and meta-analyses and systematic reviews have found mixed results.[36,37,39,46,178,179] The most recent Cochrane review of aphasia therapy noted that although there is some evidence supporting intensive treatments, there were more drop-outs in intensive treatment arms.[46] This raises questions about who might benefit most from ICAPs. ICAPs have developed as a means to fill a gap in service delivery. In the US, persons with aphasia and family members seek additional treatment at their own costs once insurance benefits have been used, and many

are inclined to attend self-pay programs such as ICAPs. A few programs have been in existence for several decades, but in the past 10 years, more ICAPs have developed through rehabilitation hospitals or university training clinics.[50] However, scant research has been published regarding programs such as this ICAP at the Rehabilitation Institute of Chicago. Potential participants ask questions regarding outcomes to weigh the cost-benefit ratio before deciding to attend. Reporting on outcomes may give other funding sources information that will determine future reimbursement. Published studies demonstrate that participants taking part in ICAPs do make significant gains in impairment and participation measures.[72,73,74] Other studies reporting on intensive research protocols have found similar results.[43,55-57,156] However, emerging research comparing intensive to non-intensive treatment using an ICAP model has shown that participants in the distributed arm made more gains than participants in the intensive arm, indicating that evidence does not equivocally support intensive treatment.[43]

6.2 Summary of Major Findings

Study One described in Chapter Two examined retrospective data to analyze changes on behavioral language impairment measures and self- and family-reports of participation.[112] The behavioral language impairment measures included auditory comprehension, verbal expression, reading and writing, and naming. Participation was rated using assessments that measured communication confidence, quality of communicative life, and communicative effectiveness. There were significant differences from pre- to post-treatment with improved scores on all measures and medium to large effect sizes. It was noted that not all participants made changes in all areas. Study Two (Chapter Three) examined the data further to determine whether there were any factors which would contribute to a model that could predict who would make significant change.[150] A ≥ five-point change on the WAB-R AQ score was considered to be a significant change. There were a range of variables that might be able to predict significant outcomes: age, time post-onset, measures of auditory comprehension and verbal expression, naming, non-verbal cognitive task, communication confidence, quality of life, and communication effectiveness. Only one factor, age, reached significance in predicting which participants made ≥ five-point change. There was also a significant difference between responders and non-responders for time post-onset with responders averaging a longer time post-onset.

Studies Three and Four (Chapters Four and Five) took a much different approach to analyzing the outcomes from this program by asking primary stakeholders to describe their

experiences through qualitative interviews.[75] Chapter Four describes the themes found after coding interviews with the clinicians who had worked in ICAPs. The main themes identified were: *the intensive therapy, rewards, and challenges*. Chapter Five describes the experiences of the participants and family members. The main themes they described in their interviews included the *intensiveness of therapy, relationships, and outcomes*. An overarching theme that linked the three themes together was one of a therapeutic milieu. Participants and family members described how the physical space and the social interactions in combination with the intensive treatment led to improved outcomes after taking part in the program.

The findings were then separated into those that described the structures, processes, and outcomes of an ICAP. The intention is to enable other service providers and consumers to extract findings that will help them identify the special structures, define the processes, and describe and predict the outcomes of an ICAP.

6.3 Structure of ICAPs

The structure of a setting includes factors related to materials, cost, facility, and staffing. The ICAP requires participants to pay out of pocket, and this leads to participants self-selecting whether they will attend or not. Clinicians and family members talked about the participants having a great amount of self-motivation, as did participants themselves. Interestingly, only one participant remarked on the cost of the program, (P09), who had a hard time adjusting to the program initially. The decision to self-pay may have resulted in highly motivated participants. The mental and physical stamina required to tolerate full-time treatment may signal that these participants have fewer comorbidities. This could be a reason behind the results from Study Two (Chapter Three) in which the only predictor of responders was being younger and possibly being further along post-stroke.

While age may impact a person's responsiveness to treatment, this study examined age in relation to only one impairment-based outcome measure, the WAB-R AQ. It may be that age does not have predictive value in who makes changes on other impairment or participation outcome measures. In general, other research regarding stroke and aphasia has concluded that factors such as age, gender, education, site and size of lesion, cannot consistently predict outcomes.[77,81,114-116] In contrast, two studies examining predictors in patients with aphasia found that better scores on a composite measure of phonology and non-linguistic cognitive markers predicted better outcomes one year post-stroke.[77,115]

Persad and colleagues looked at predictors in two different ICAPs and similarly found that there was no difference between responders and non-responders on the WAB-R AQ on factors of age, time post-onset, and gender, but did find a difference in severity of aphasia.[73] Similar to this thesis, there was a trend towards older participants who were longer time post-onset having less change on the AQ measure. In many studies predicting outcomes, the type and amount of treatment administered between the designated time points is not specifically known. For example one study reported a range of 3-83 hours over a period of a year.[115] These factors of cost (which requires greater resources) and related participant characteristics appeared to influence outcomes.

The qualitative findings also suggested some other structural factors that were important for good outcomes from an ICAP. Clinicians were experienced and motivated. They were required to have at least three years of clinical experience, they self-selected to work in the ICAP, and many had worked with more than one cohort. Study Three (Chapter Four) outlines the rewards the clinicians obtained from working in ICAPs which included providing therapy at a "deeper" level, developing stronger relationships with participants and families, learning about evidence-based treatments, and learning from colleagues. In participant and family member interviews, they commented on the clinicians' years of experience, positivity, and engagement (see Chapter Five). Family members also commented on the quality of the administrative staff and processes for the ICAP which were considered to be factors that also contributed to their satisfaction with the program.

Participants and family members noted differences in the structure of the treatment environment compared to usual aphasia therapy settings. The family room allowed for relationships to develop; however, some did mention the family room was too small, and may not have stayed in the room to take part in conversations with others. Some noted that being in an office building gave the participant a sense of going to work. Anecdotally, one participant attended his twice-weekly therapy sessions at a day rehabilitation program in gym clothing, but when he attended the ICAP, he dressed in slacks, sweaters, and button-down shirts. Two participants and family members described attending the program as going to "work". Additionally, comments about the environment ranged from discussing the macro-environment of being in a large city which impacted both psychosocial (increased confidence in navigating the city) and physical (more walking) characteristics for the person with aphasia, to the small-scale micro-environment of the family room, which impacted the

psychosocial health of family members by providing a dedicated space in which they received or gave social support.

6.4 Process of Therapy in ICAPs

The process of therapy in this ICAP (the act of giving and receiving therapy) consisted of intensive, high dose, individualized evidence-based treatment. There has been considerable discussion and investigations into the intensity and dose of aphasia treatment recently, as there is no consistent definition of intensity.[38,108] One study may define intensity as one hour a day for four weeks, and another study may define intensity as three hours a day for two weeks.[38,108] Brady et al in the most recent Cochrane review only described the effect of "intensity" on outcomes while the issue of "intensiveness" or the total number of hours of therapy over the course of a time span did not received as much attention. The Therapeutic Intensity Ratio (TIR) describes the "intensiveness" of treatment, that is, the number of treatment hours in one week divided by the potential number of treatment hours (40 hours) per week.[112] The RIC ICAP has a TIR of 75%, providing 30 hours of therapy a week for a total of 120 hours of therapy. Other clinical ICAP studies with positive outcomes have reported an average of 121 hours of therapy over five weeks with an average TIR of 61%.[72-74] Usual care in the US provides an average of 5% TIR (approximately two hours per week). Previous research has found that treatments which provided an average of 22% TIR (8.8 hrs. per week over 11.2 weeks, 98.75 total hrs.) demonstrated better outcomes than treatment that provided 5% TIR (2 hrs. per week over 22.9 weeks, 45.8 total hrs.). One study has examined the effects of the TIR by comparing 48 hours of therapy delivered over three weeks and eight weeks (TIR of 40% and 15% respectively).[43] The authors found that the distributed arm demonstrated significant gains on a naming outcome measure when compared to the intensive arm. We suggest that researchers begin to include this measure of intensiveness which provides more description of the processes that are occurring when the treatment in question is administered. Also, including this additional characteristic would allow for better comparisons of studies as it is difficult to compare studies that are researching "intensity."

Another feature of ICAPS is that it combines several evidence-based treatments into a package. Our findings suggest that the clinicians involved in the ICAPS are not providing this type of treatment in everyday practice. The ICAP provided specialized training in evidence-based practice to the speech-language pathologists. Daily meetings of the clinical team were another process that enabled the treatments to be individualized for each

participant. The meetings were held twice a day to review participant goals and discuss treatment ideas which clinicians felt led to better outcomes for the participant and contributed to being a better clinician in their regular setting. It was noted by some participants or family members that the clinicians had more knowledge and could target very specific language deficits. This strong knowledge base was viewed very positively and participants remarked that the therapy was "hard" and "challenged the brain." Participants commented that the quick pace of the therapy by snapping their fingers, or saying "happening", something that was different from previous therapy. About half of the participants (n=5) referred to the length of the day and being tired. The intensity of the treatment was one aspect that was most commented on which is not surprising. Many participants; however, indicated that they would like the program to go longer. The intensity of treatment was a theme that was significantly commented on by clinicians, and they echoed the participants and family members as they felt they could go "deeper" with their treatments. This was a function of having two individual sessions per day, totaling up to 40 hours of individual impairment-based treatment over the four weeks.

6.5 Outcomes

The analysis of pre- to post-treatment demonstrated significant changes on evaluation measures. Outcomes were also discussed by all stakeholders in the interviews. Participants and family members specifically mentioned improvements in language, which was reflective of the improvements seen on the impairment-based measures reported in Study One (Chapter Two). Many participation outcomes were also mentioned, and they felt improvements in that area were a direct result of taking part in the program. These activities ranged from ordering at coffee shops, talking on the phone with friends, and doing language-based pre-stroke leisure activities like crossword puzzles. Positive outcomes reported by participants and family members included improved language, stronger relationships, improved psychosocial health, and improved physical abilities.

Only a few family members indicated that they expected to see improvements or positive outcomes. However, many others said that before attending, they either had no expectations or they "hoped for" or "wanted to see" improvements related to language or communication outcomes.

For the clinicians, comments about outcomes related to changed clinical practice in both impairment- and participation-based activities. Working in the ICAP gave them the

opportunity to learn evidence-based treatments and use them in clinical practice, modify clinical practice to provide more repetitions in sessions, incorporate more detailed home programs, and recommend groups for their clients with aphasia. They also reported positive outcomes for their clients and felt rewarded as clinicians when seeing improvements in their clients and developing deeper relationships.

While there have been critiques of Donabedian's model over the years, it is important to note that the first iteration was described in the mid-1960s. In 1988, Donabedian acknowledged that more information was needed across the spectrum of measurement of quality in health care including interpersonal interactions of the practitioner and patient to interaction with the community and provision of care. Instead of viewing the model as not relevant, some have expanded the model to demonstrate that the basic structure is still applicable and has evolved to incorporate the complexities of health care. Qu and colleagues conducted a retrospective study to analyze outcome data from spinal cord injury patients in the context of the structure and process.[180] Their aim was to identify other factors that may contribute to the model of measuring outcomes following inpatient rehabilitation. The model they examined included environmental (i.e., policy and payment systems) and patient characteristics (i.e., initial severity). Their multi-level analyses demonstrated that outcomes were impacted by factors that are typically considered outside of the structure and process of an organization. Additionally, client characteristics may be important to include in a model of what contributes to the outcomes from an ICAP. These additions to the Donabedian model (participant characteristics, structures, and processes outside the organization) are relevant to ICAPs.

Clinicians, participants, and family members all reported high levels of satisfaction with the ICAP model and reported that the intensity factor was difficult, but overall worth it. The fact that there were no drop-outs during any of the cohorts demonstrated satisfaction with the treatment. In their systematic reviews of randomized control trials of aphasia treatment Brady et al noted that there was a higher drop-out rate in intensive arms of research studies.[46] Drop-outs were rarely reported by other studies of ICAPs. Perhaps this is due to differences in the chronicity of the participants. Participants in this ICAP were on average 15.5 months post-onset, as compared to treatments that were administered in sub-acute or early rehabilitation settings. They were not accepted into the program unless they were physically able to tolerate intensive therapy Brady also suggested that outcomes from aphasia treatments should assess psychosocial impact (i.e. impact on psychological or

social well-being including mood, depression, anxiety, and distress), and satisfaction with intervention. As we found, participants and family members commented on the importance of the relationships, improved mood, reduced stress, and anxiety which may have impacted their satisfaction with the ICAP. Wallace and colleagues used nominal group techniques to ask persons with aphasia and family members what were important outcomes from aphasia rehabilitation.[153] Improved communication (e.g., speaking in longer words/sentences, using technology, participating in conversation) was highlighted as the most important outcome. This theme was also highlighted as an important outcome after taking part in an ICAP during our interviews. Wallace, et. al., also found that improved physical and emotional well-being was an important outcome to persons with aphasia and family members. Again, this was found to be an outcome of the ICAP. Using the Donabedian model, the structure and processes of this ICAP facilitated outcomes that were meaningful to the person with aphasia and family members. It may be appropriate in the future to measure self-reports of improved psychosocial health and improved physical functioning.

6.6 Therapeutic Milieu

The previous section described how the structure and process of an ICAP provided a different treatment model which impacted outcomes for participants, family members and clinicians. An overarching theme from the studies in this thesis was that an ICAP provides a therapeutic environmental milieu that is a specialized model of therapy. The therapeutic milieu was not only comprised of the language treatment, but encompassed the physical and social environments which contributed to positively reported outcomes from the participants, family members, and clinicians. Earlier work by researchers in other fields incorporated social milieu as one of the primary domains in environments in which people live and work.[181,182] By analyzing only behavioral language impairment changes and participation rating scales, the concept of the therapeutic milieu would not have been identified.

The concept of therapeutic milieu illustrates how this ICAP led to improved psychosocial health and physical activities, along with the impairment and participation outcomes. For example, interviews allowed participants and family members to describe how the physical environment brought people together for extended periods of time and allowed for deeper friendships and relationships to develop. Clinicians talked about how the deeper relationships with their clients led to more satisfaction when providing therapy. Participants and family members repeatedly indicated that the therapeutic milieu of the ICAP provided

benefits to their psychosocial health. They talked about being around others with the same condition, support they gave and received, and networks of persons who helped them. Social support has been defined as incorporating different types of support which could be emotional (empathy, trust, caring), instrumental (tangible aid), informational (advice, suggestions), and appraisal (information for self-evaluation).[183,184] Participants and family members described how they benefited from all of these types of social support while taking part in this ICAP.[184] Heaney and Israel (2008) described structural and functional characteristics of social networks to include concepts such as intensity (emotional closeness), density (knowing and interacting with each other), homogeneity (demographic similarity), geographical dispersion (close proximity), and companionship (shared leisure activities). These characteristics of social networks were described as part of the ICAP in the interviews with participants and family members. This reinforces the importance and strength of the social networks that were formed during the program. Heaney and Israel's concepts of social networks also includes physical proximity, which was important in this ICAP. Social support has also been described as a key factor in mediating recovery from traumatic health events.[183,185] It has been identified as a key factor contributing to post-traumatic growth (PTG) in many health conditions, not only in patients, but also in care-givers' growth following the illness of a family member.[186-190] There is minimal literature about mediators for PTG in stroke and no research as to whether the same mediators apply to persons with aphasia.[191,192]

It is contended that the therapeutic milieu is created by the "program" part of the ICAP acronym. Participants and their families all start and end the program together. They share the journey. Many of the social interactions happened outside the therapy rooms and beyond the therapy setting as many of the social interactions happened outside. Participants and families frequently met for dinner and activities over the weekend. One family member who lived in the area, but was working, said she missed those opportunities to interact with other family members. She also commented about the importance of those experiences as she had those kinds of interactions with families and friends of her disabled son. A few participants commented that they had attended aphasia groups in their home town, but the schedule of one hour a week did not allow for really getting to know others with aphasia. It appears that the opportunity to connect over an extended time period with others going through similar experiences was an important component of this environment. While research has not been conducted specifically regarding post-traumatic growth in aphasia, other qualitative research has described the importance of social networks and support

regarding recovery and aphasia treatments. Participants in Tomkins' interviews found that in terms of Donabedian's model, positive experiences with aspects of the process led to satisfaction with treatment. This included therapy that they felt respected their individuality, service delivery that was caring, provision of information that was meaningful, and perceived improvements that contributed to satisfaction with health care.[154] Positive experiences with factors related to the social milieu were also described as contributing to satisfaction with therapy: having genuine relationships with the therapist, receiving support from the therapy staff, and positivity and hope from medical staff also contributed to psychosocial health, similar to what was found in the interviews. Other qualitative and quantitative research has found that participants and family members endorse the importance of social networks and that a lack of social networks/support can lead to poor psychosocial health and poor quality of life.[12,48,68,117,172,193,194]

6.6.1 Limitations

The limitations of each study are outlined within each report of each of the studies. In general, a lack of scientific rigor is unavoidable in examining outcomes for a clinical treatment program that is already in practice. The analysis of the database was retrospective. There was no randomization of the participants, and while there was a range of age, time post-onset, and severity of aphasia, the demographic characteristics of the participants were narrow in terms of race/ethnicity, education, and professional background. In a prospective research study, it may be important to screen for cognitive deficits, multiple strokes, seizures, and other neurological deficits. It may also be necessary to broaden the demographic characteristics. Another confounding factor is that treatment is highly individualized. Treatments may have been adapted to address specific deficits for that individual. Different clinicians may implement a treatment slightly differently than another clinician. However, modifications were based on clinical judgment and daily conversations reflected a consensus among the clinicians about appropriate modifications. A treatment fidelity protocol may need to be implemented in a prospective study.

Hula et al described the phased research approach to evaluate complex interventions such as ICAPs.[71] The database analysis is the first stage of such a process, and has provided a proof-of-concept.[112] The main limitations in the quantitative analysis regarding scientific rigor are: no control group, no comparison to usual care, lack of blinding of the clinicians, and self-selection of the participants.[71]

Chapter Two describes in detail how the program structure was modified from traditional treatment provided by the hospital and highlights some of the obstacles in the logistics of implementing an intensive program. However, the issues that arise in continued research with the ICAP model are that there are multiple evidence-based treatments implemented and individualized for each participant, the staff are specifically trained in those treatments, and the treatment is administered for several hours a day. It is impossible to tease out the salient factors that impact treatment. Additionally, the social and physical environment was reported to have significant impact on psychosocial health; however, measurement of those factors was not included because the extent of the impact was not known. Another aspect that was not measured but would give more information about outcomes would be to obtain self-ratings from family members about their quality of life, stress levels, and psychosocial health. Given that family members are considered to have third-party disability, addressing their needs may also promote change that would positively impact on person with aphasia.[157,158,195]

6.6.2 Future research

Currently, reimbursement for health care services is dependent on impairment-based outcome measures. As health care moves towards including self-reports of improvements and patient satisfaction as outcomes of medical treatment, it will be important to examine other factors in the structure and process of a treatment which may also have significant impact on those types of outcomes and be able to develop treatments that maximize those outcome for greatest number of persons.[34,196] Given that significant changes were noted for both the participants and the family members, it appears that this model of treatment is one approach to optimize recovery for persons with aphasia.

The therapeutic milieu finding needs further investigation. The social-ecological research methodology may provide insight into measuring the social and physical milieu of an intensive program to help determine which aspects provide for the psychosocial needs of the participants and the family members.[181,182,197] Moos and Lemke developed models of measuring the physical attributes and social interactions that occur in facilities for the elderly. Their research and conceptual framework found that physical and architectural features, organizational policies, and person characteristics were intertwined with the social environment.[198] This model could be used to identify whether specific factors are present in the physical environment and social climate which result in satisfaction with health services.[154]

Since ICAPs are already in operation, outcome measurement is important to determine sustainability and inform consumers and future payers. The results of this study demonstrated that it is the whole "package" of treatment, or the therapeutic milieu, that leads to significant outcomes which are important to the stakeholders. Analysis of outcomes of this "therapeutic package" may benefit from practice-based research methodology. Practice-based research provides a basis for examining treatments that are administered to a range of patient demographics to examine the effectiveness of a treatment in every day practice. Crooke and Olswang support incorporating practice-based research as an alternative, complementary research approach that addresses "clinical questions that focus on intervention protocols used in everyday settings."[199] Horn and colleagues also note that studies using this research method "answer questions in the real world where multiple variables and factors can affect the outcomes, and therefore have the potential to influence and improve real world clinical care for the benefit of the patients.[200] Given the complex nature of intensive comprehensive aphasia treatment, practice-based research would allow for the variation in participant demographics and the inclusion of a variety of treatments. A database of structures, processes, and outcomes from many different ICAPS would enable some real-world questions about ICAPs (e.g. optimal dose and intensity) to be investigated further.

6.7 Conclusion

Given that the participants and families were dealing with a traumatic health event, this ICAP provided a therapeutic milieu which allowed for more supportive relationships to develop in addition to receiving language- and participation-based treatment. The qualitative comments about impairment and participation outcomes reflected the significant gains that the language-based evaluations and self-rating measures demonstrated. This thesis has shown that Donabedian's model of how changes to the structure and process of a treatment can impact outcomes is a viable model. The changes implemented in this ICAP had wide-reaching impact as indicated by data-driven outcomes and described by the stakeholders' experiences. Clinicians, persons with aphasia, and family members all indicated improvement in language and participation, which was expected given that there were significant differences noted in the database analysis changes from pre- to post-treatment. Using both approaches, quantitative and qualitative, allowed for a broader examination of the outcomes and demonstrated that the qualitative interviews substantiated the findings from quantitative analysis. However, the qualitative interviews added more depth to the analysis of what constitutes outcomes from an ICAP. The additional findings of how the

physical and social environments contributed to outcomes in psychosocial and physical health domains, indicates that the ICAP provides a therapeutic milieu which has important impacts on the participants and family members.

References

1. Benjamin EJ, Blaha MJ, Chiuve SE, et al. Heart Disease and Stroke Statistics-2017 Update: A Report From the American Heart Association. *Circulation.* 2017.
2. Collaborators USBoD. The state of US health, 1990-2010: burden of diseases, injuries, and risk factors. *JAMA.* 2013;310(6):591-608.
3. Ellis C, Dismuke C, Edwards KK. Longitudinal trends in aphasia in the United States. *NeuroRehabilitation.* Vol 27. Netherlands2010:327-333.
4. Cruice M, Worrall L, Hickson L. Perspectives of quality of life by people with aphasia and their family: suggestions for successful living. *Top Stroke Rehabil.* 2006;13(1):14-24.
5. Graham JR, Pereira S, Teasell R. Aphasia and return to work in younger stroke survivors. *Aphasiology.* 2011;25(8):952-960.
6. Le Dorze G, Brassard C. A description of the consequences of aphasia on aphasic persons and their relatives and friends, based on the WHO model of chronic diseases. *Aphasiology.* 1995;9(3):239-255.
7. Northcott S, Hilari K. Why do people lose their friends after a stroke? *Int J Lang Commun Disord.* 2011;46(5):524-534.
8. Le Dorze G, Salois-Bellerose É, Alepins M, Croteau C, Hallé M-C. A description of the personal and environmental determinants of participation several years post-stroke according to the views of people who have aphasia. *Aphasiology.* 2014;28(4):421-439.
9. Tsouna-Hadjis E, Vemmos KN, Zakopoulos N, Stamatelopoulos S. First-stroke recovery process: the role of family social support. *Arch Phys Med Rehabil.* 2000;81(7):881-887.
10. Hilari K, Northcott S, Roy P, et al. Psychological distress after stroke and aphasia: the first six months. *Clin Rehabil.* 2010;24(2):181-190.
11. Cruice M, Worrall L, Hickson L. Reporting on psychological well-being of older adults with chronic aphasia in the context of unaffected peers. *Disabil Rehabil.* 2011;33(3):219-228.
12. Northcott S, Moss B, Harrison K, Hilari K. A systematic review of the impact of stroke on social support and social networks: Associated factors and patterns of change. *Clin Rehabil.* 2015.
13. Lee H, Lee Y, Choi H, Pyun SB. Community Integration and Quality of Life in Aphasia after Stroke. *Yonsei Med J.* 2015;56(6):1694-1702.
14. *National Outcomes Measurement System: Adults in Healthcare - Outpatient National Data Report 2011.* Rockville, MD: American Speech-Language-Hearing Association;2011.
15. Katz RC, Hallowell B, Code C, et al. A multinational comparison of aphasia management practices. *Int J Lang Commun Disord.* 2000;35(2):303-314.
16. Rose M, Cherney LR, Worrall L. Intensive comprehensive aphasia rehabilitation programs (I-CAPs): An international survey of practice. *Top Stroke Rehabil.* 2013.
17. Üstün TB, Chatterji S, Bickenbach J, Kostanjsek N, Schneider M. The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disabil Rehabil.* 2003;25(11-12):565-571.
18. Worrall L, Sherratt S, Rogers P, et al. What people with aphasia want: Their goals according to the ICF. *Aphasiology.* 2011;25(3):309-322.
19. Rohde A, Townley-O'Neill K, Trendall K, Worrall L, Cornwell P. A comparison of client and therapist goals for people with aphasia: A qualitative exploratory study. *Aphasiology.* 2012;26(10):1298-1315.
20. O'Halloran R, Worrall L, Hickson L. Stroke patients communicating their healthcare needs in hospital: a study within the ICF framework. *Int J Lang Commun Disord.* 2012;47(2):130-143.
21. Simmons-Mackie N, Kagan A. Application of the ICF in aphasia. Paper presented at: Seminars in speech and language2007.

22. Kagan A, Simmons-Mackie N, Rowland A, et al. Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology.* 2008;22(3):258-280.
23. Kagan A, Simmons-Mackie N, Rowland A, et al. Assessment for living with aphasia. *Toronto, ON: Aphasia Institute.* 2010.
24. Dictionary MWO. Outcome. n.d.; http://www.merriam-webster.com/dictionary/outcome. Accessed 11/17/16.
25. Donabedian. Evaluating the quality of medical care. *The Milbank memorial fund quarterly.* 1966;44(3):166-206.
26. Donabedian. The quality of care. How can it be assessed? *JAMA.* 1988;260(12):1743-1748.
27. Heinemann AW. Putting outcome measurement in context: A rehabilitation psychology perspective. *Rehabil Psychol.* 2005;50(1):6.
28. Hoenig H, Lee J, Stineman M. Conceptual overview of frameworks for measuring quality in rehabilitation. *Top Stroke Rehabil.* 2010;17(4):239-251.
29. McAuliffe WE. Measuring the quality of medical care: process versus outcome. *The Milbank Memorial Fund Quarterly Health and Society.* 1979:118-152.
30. Iezzoni LI, Shwartz M, Ash AS, Mackiernan Y, Hotchkin EK. Risk adjustment methods can affect perceptions of outcomes. *Am J Med Qual.* 1994;9(2):43-48.
31. Iezzoni LI. Using risk-adjusted outcomes to assess clinical practice: an overview of issues pertaining to risk adjustment. *Ann Thorac Surg.* 1994;58(6):1822-1826.
32. Mitchell PH, Ferketich S, Jennings BM. Quality health outcomes model. *Image: The Journal of Nursing Scholarship.* 1998;30(1):43-46.
33. Clancy CM, Eisenberg JM. Outcomes research: measuring the end results of health care. *Science.* 1998;282(5387):245-246.
34. Cella D, Riley W, Stone A, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *J Clin Epidemiol.* 2010;63(11):1179-1194.
35. Kleim JA, Jones TA. Principles of experience-dependent neural plasticity: implications for rehabilitation after brain damage. *Journal of Speech, Language and Hearing Research.* 2008;51(1):S225.
36. Bhogal SK, Teasell RW, Foley NC, Speechley MR. Rehabilitation of aphasia: more is better. *Top Stroke Rehabil.* 2003;10(2):66-76.
37. Bhogal SK, Teasell R, Speechley M. Intensity of aphasia therapy, impact on recovery. *Stroke.* 2003;34(4):987-993.
38. Baker E. Optimal intervention intensity. *Int J Speech Lang Pathol.* 2012;14(5):401-409.
39. Cherney L, Patterson J, Raymer A, Frymark T, Schooling T. Updated evidence-based systematic review: Effects of intensity of treatment and constraint-induced language therapy for individuals with stroke-induced aphasia. *Rockville Pike, MD: American Speech-Language-Hearing Association Available online at: http://www asha org/uploadedFiles/EBSR-Updated-CILT pdf# search=% 22EBSR.* 2010;22.
40. Cherney LR. Aphasia treatment: Intensity, dose parameters, and script training. *Int J Speech Lang Pathol.* 2012;14(5):424-431.
41. Cherney LR, Patterson JP, Raymer AM. Intensity of Aphasia Therapy: Evidence and Efficacy. *Curr Neurol Neurosci Rep.* 2011;11(6):560-569.
42. Worrall LE, Hudson K, Khan A, Ryan B, Simmons-Mackie N. Determinants of Living Well With Aphasia in the First Year Poststroke: A Prospective Cohort Study. *Arch Phys Med Rehabil.* 2017;98(2):235-240.
43. Dignam J, Copland D, McKinnon E, et al. Intensive Versus Distributed Aphasia Therapy: A Nonrandomized, Parallel-Group, Dosage-Controlled Study. *Stroke.* 2015.

44. Allen L, Mehta S, McClure JA, Teasell R. Therapeutic interventions for aphasia initiated more than six months post stroke: A review of the evidence. *Top Stroke Rehabil.* 2012;19(6):523-535.
45. Allen L, Mehta S, McClure JA, Teasell R. Therapeutic interventions for aphasia initiated more than six months post stroke: a review of the evidence. *Top Stroke Rehabil.* 2012;19(6):523-535.
46. Brady MC, Kelly H, Godwin J, Enderby P, Campbell P. Speech and language therapy for aphasia following stroke. *Cochrane Database Syst Rev.* 2016(6):Cd000425.
47. Chapey R, Duchan J, Elman R, Garcia L, Kagan AL. "Life participation approach to aphasia: A statement of values for the future.". *Language intervention strategies in aphasia and related neurogenic communication disorders.* 2001:235-245.
48. Brown K, Worrall LE, Davidson B, Howe T. Living successfully with aphasia: a qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. *Int J Speech Lang Pathol.* 2012;14(2):141-155.
49. Brown K, Worrall L, Davidson B, Howe T. Snapshots of success: An insider perspective on living successfully with aphasia. *Aphasiology.* 2010;24(10):1267-1295.
50. Rose ML, Cherney LR, Worrall LE. Intensive comprehensive aphasia programs: An international survey of practice. *Top Stroke Rehabil.* 2013;20(5):379-387.
51. Attard MC, Lanyon L, Togher L, Rose ML. Consumer perspectives on community aphasia groups: a narrative literature review in the context of psychological well-being. *Aphasiology.* 2015;29(8):983-1019.
52. Rotherham A, Howe T, Tillard G. "We just thought that this was Christmas": perceived benefits of participating in aphasia, stroke, and other groups. *Aphasiology.* 2015;29(8):965-982.
53. Johansson MB, Carlsson M, Sonnander K. Working with families of persons with aphasia: a survey of Swedish speech and language pathologists. *Disabil Rehabil.* 2011;33(1):51-62.
54. Howe T, Davidson B, Worrall L, et al. 'You needed to rehab ... families as well': family members' own goals for aphasia rehabilitation. *Int J Lang Commun Disord.* 2012;47(5):511-521.
55. Code C, Torney A, Gildea-Howardine E, Willmes K. Outcome of a one-month therapy intensive for chronic aphasia: Variable individual responses. *Semin Speech Lang.* 2010;31(01):021-033.
56. Mackenzie C. An aphasia group intensive efficacy study. *Int J Lang Commun Disord.* 1991;26(3):275-291.
57. Rodriguez AD, Worrall L, Brown K, et al. Aphasia LIFT: Exploratory investigation of an intensive comprehensive aphasia programme. *Aphasiology.* 2013;27(11):1339-1361.
58. Whyte J, Gordon W, Gonzalez Rothi LJ. A phased developmental approach to neurorehabilitation research: The science of knowledge building. *Arch Phys Med Rehabil.* 2009;90(11):S3-S10.
59. Creswell J. Qualitative inquiry and research method: Choosing among five approaches. Thousand Oaks, CA: Sage; 2007.
60. Giorgi A. The phenomenological movement and research in the human sciences. *Nurs Sci Q.* 2005;18(1):75-82.
61. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. *The qualitative researcher's companion.* 2002;573:305-329.
62. Ritchie J, Lewis J, Nicholls CM, Ormston R. *Qualitative research practice: A guide for social science students and researchers.* Sage; 2013.
63. Ohman A. Qualitative methodology for rehabilitation research. *J Rehabil Med.* 2005;37(5):273-280.

64. Magasi S, Hammel J, Heinemann A, Whiteneck G, Bogner J. Participation: a comparative analysis of multiple rehabilitation stakeholders' perspectives. *J Rehabil Med.* 2009;41(11):936-944.
65. Brown K, Worrall L, Davidson B, Howe T. Living successfully with aphasia: family members share their views. *Top Stroke Rehabil.* 2011;18(5):536-548.
66. Brown K, Worrall L, Davidson B, Howe T. Exploring speech-language pathologists' perspectives about living successfully with aphasia. *Int J Lang Commun Disord.* 2011;46(3):300-311.
67. Hjelmblink F, Bernsten CB, Uvhagen H, Kunkel S, Holmström I. Understanding the meaning of rehabilitation to an aphasic patient through phenomenological analysis-a case study. *International Journal of Qualitative Studies on Health and Well-being.* 2007;2(2):93-100.
68. Dalemans RJ, de Witte L, Wade D, van den Heuvel W. Social participation through the eyes of people with aphasia. *Int J Lang Commun Disord.* 2010;45(5):537-550.
69. Grohn B, Worrall LE, Simmons-Mackie N, Brown K. The first 3-months post-stroke: what facilitates successfully living with aphasia? *Int J Speech Lang Pathol.* 2012;14(4):390-400.
70. World Health Organization [WHO]. International classification of functioning disability and health (ICF). 2001; http://www.who.int/classifications/icf/en/.
71. Hula WD, Cherney LR, Worrall LE. Setting a Research Agenda to Inform Intensive Comprehensive Aphasia Programs. *Top Stroke Rehabil.* 2013;20(5):409-420.
72. Hinckley JJ, Craig HK. Influence of rate of treatment on the naming abilities of adults with chronic aphasia. *Aphasiology.* 1998;12(11):989-1006.
73. Persad C, Wozniak L, Kostopoulos E. Retrospective analysis of outcomes from two intensive comprehensive aphasia programs. *Top Stroke Rehabil.* 2013;20(5):388-397.
74. Winans-Mitrik RL, Hula WD, Dickey MW, Schumacher JG, Swoyer B, Doyle PJ. Description of an intensive residential aphasia treatment program: Rationale, clinical processes, and outcomes. *Am J Speech Lang Pathol.* 2014;23(2):S330-S342.
75. Babbitt EM, Worrall LE, Cherney LR. Clinician Perspectives of an Intensive Comprehensive Aphasia Program. *Top Stroke Rehabil.* 2013;20(5):398-408.
76. Campbell M, Fitzpatrick R, Haines A, et al. Framework for design and evaluation of complex interventions to improve health. *BMJ: British Medical Journal.* 2000;321(7262):694.
77. El Hachioui H, Visch-Brink EG, Lingsma HF, et al. Nonlinguistic cognitive impairment in poststroke aphasia: a prospective study. *Neurorehabil Neural Repair.* 2014;28(3):273-281.
78. Lazar RM, Antoniello D. Variability in recovery from aphasia. *Curr Neurol Neurosci Rep.* 2008;8(6):497-502.
79. Votruba KL, Rapport LJ, Whitman RD, Johnson A, Langenecker S. Personality differences among patients with chronic aphasia predict improvement in speech-language therapy. *Top Stroke Rehabil.* 2013;20(5):421-431.
80. Basso A. Prognostic factors in aphasia. *Aphasiology.* 1992;6(4):337-348.
81. Plowman E, Hentz B, Ellis C. Post-stroke aphasia prognosis: a review of patient-related and stroke-related factors. *J Eval Clin Pract.* 2012;18(3):689-694.
82. El Hachioui H, Lingsma HF, van de Sandt-Koenderman ME, Dippel DW, Koudstaal PJ, Visch-Brink EG. Recovery of aphasia after stroke: a 1-year follow-up study. *J Neurol.* 2013;260(1):166-171.
83. Lazar RM, Minzer B, Antoniello D, Festa JR, Krakauer JW, Marshall RS. Improvement in aphasia scores after stroke is well predicted by initial severity. *Stroke.* 2010;41(7):1485-1488.
84. Wallesch C-W, Bak T, Schulte-Mönting J. Acute aphasia–patterns and prognosis. *Aphasiology.* 1992;6(4):373-385.

85. Wendt O, Koul R, Hassink JM. Time post-onset does not affect response to treatment in patients with chronic aphasia≥ 1 year after stroke 1. *Evidence-Based Communication Assessment and Intervention.* 2008;2(4):199-202.
86. Kertesz A. *Western Aphasia Battery -Revised.* San Antonio, TX: PsychCorp; 2007.
87. Goodglass H, Kaplan E, Weintraub S, Segal O. *Boston naming test.* Lippincott Williams & Wilkins; 2001.
88. Babbitt EM, Heinemann AW, Semik P, Cherney LR. Psychometric properties of the Communication Confidence Rating Scale for Aphasia (CCRSA): Phase 2. *Aphasiology.* 2011;25(6-7):727-735.
89. Lomas J, Pickard L, Bester S, Elbard H, Finlayson A, Zoghaib C. The communicative effectiveness index: Development and psychometric evaluation of a functional communication measure for adult aphasia. *Journal of Speech and Hearing Disorders.* 1989;54(1):113.
90. Paul DR, Frattali CM, Holland AL, Thompson CK, Caperton CJ, Slater SC. Quality of Communication Life Scale. Rockville, MD: American Speech-Language-Hearing Association; 2005.
91. Dabul B. Apraxia battery for adults. 2nd. *Austin: Pro-Ed.* 2000.
92. Wambaugh JL, Duffy JR, McNeil MR, Robin DA, Rogers MA. Treatment guidelines for acquired apraxia of speech: A synthesis and evaluation of the evidence. 2006.
93. Boyle M. Semantic Feature Analysis Treatment for Aphasic Word Retrieval Impairments: What's in a Name? *Top Stroke Rehabil.* 2010;17(6):411-422.
94. Edmonds LA, Nadeau SE, Kiran S. Effect of Verb Network Strengthening Treatment (VNeST) on lexical retrieval of content words in sentences in persons with aphasia. *Aphasiology.* 2009;23(3):402-424.
95. Kendall DL, Hunting Pompon R, Brookshire EC, Minkina I, Bislick L. An Analysis of Aphasic Naming Errors as an Indicator of Improved Linguistic Processing Following Phonomotor Treatment. *Am J Speech Lang Pathol.* 2013;22(2):S240-S249.
96. Pulvermüller F, Neininger B, Elbert T, et al. Constraint-induced therapy of chronic aphasia after stroke. *Stroke.* 2001;32(7):1621-1626.
97. Rewega MA, Beeson PM, Hirsch FM. Successful single-word writing treatment: Experimental analyses of four cases. *Aphasiology.* 2002;16(4):473-491.
98. Thompson C, Shapiro L. Treating agrammatic aphasia within a linguistic framework: Treatment of Underlying Forms. *Aphasiology.* 2005;19(10-11):1021-1036.
99. Cherney LR. Oral reading for language in aphasia (ORLA): Evaluating the efficacy of computer-delivered therapy in chronic nonfluent aphasia. *Top Stroke Rehabil.* 2010;17(6):423-431.
100. Cherney LR, Halper AS, Holland AL, Cole R. Computerized script training for aphasia: Preliminary results. *Am J Speech Lang Pathol.* 2008;17(1):19.
101. Simmons-Mackie N, Elman RJ, Holland AL, Damico JS. Management of discourse in group therapy for aphasia. *Topics in Language Disorders.* 2007;27(1):5-23.
102. Murray CJ, Abraham J, Ali MK, et al. The state of US health, 1990-2010: burden of diseases, injuries, and risk factors. *JAMA.* 2013;310(6):591-606.
103. Wambaugh J, Mauszycki S, Ballard K. Advances in the Treatment for Acquired Apraxia of Speech. *SIG 2 Perspectives on Neurophysiology and Neurogenic Speech and Language Disorders.* 2013;23(3):95-119.
104. Wambaugh JL, Duffy JR, McNeil MR, Robin DA, Rogers MA. Treatment guidelines for acquired apraxia of speech: Treatment descriptions and recommendations. *Journal of Medical Speech Language Pathology.* 2006;14(2):xxxv.

105. Cohen J. Statistical power analysis for the behavioral sciences Laurence Erlbaum. *Hillsdale, NJ.* 1988.
106. Cherney LR, Halper AS, Holland AL, Lee JB, Babbitt E, Cole R. Improving conversational script production in aphasia with virtual therapist computer treatment software. *Brain Lang.* 2007;103(1):246-247.
107. Shewan CM, Kertesz A. Reliability and validity characteristics of the Western Aphasia Battery (WAB). *J Speech Hear Disord.* 1980;45(3):308.
108. Baker E. Optimal intervention intensity in speech-language pathology: discoveries, challenges, and unchartered territories. *Int J Speech Lang Pathol.* 2012;14(5):478-485.
109. Warren SF, Fey ME, Yoder PJ. Differential treatment intensity research: A missing link to creating optimally effective communication interventions. *Mental Retardation and Developmental Disabilities Research Reviews.* 2007;13(1):70-77.
110. Teasell R, Mehta S, Pereira S, et al. Time to rethink long-term rehabilitation management of stroke patients. *Top Stroke Rehabil.* 2012;19(6):457-462.
111. Dickey L, Kagan A, Lindsay MP, Fang J, Rowland A, Black S. Incidence and profile of inpatient stroke-induced aphasia in Ontario, Canada. *Arch Phys Med Rehabil.* 2010;91(2):196-202.
112. Babbitt EM, Worrall L, Cherney LR. Structure, Processes, and Retrospective Outcomes From an Intensive Comprehensive Aphasia Program. *Am J Speech Lang Pathol.* 2015;24(4):S854-863.
113. Cherney L, Robey R. Aphasia treatment: recovery, prognosis and clinical effectiveness. In: Chapey R, ed. *Language intervention strategies in aphasia and related neurogenic communication disorders*. 5th ed. Baltimore: Williams & Wilkins; 2008:186-202.
114. Watila MM, Balarabe SA. Factors predicting post-stroke aphasia recovery. *J Neurol Sci.* 2015;352(1-2):12-18.
115. El Hachioui H, Lingsma HF, van de Sandt-Koenderman MW, Dippel DW, Koudstaal PJ, Visch-Brink EG. Long-term prognosis of aphasia after stroke. *J Neurol Neurosurg Psychiatry.* 2013;84(3):310-315.
116. Goldstein FC, Levey AI, Steenland NK. High blood pressure and cognitive decline in mild cognitive impairment. *J Am Geriatr Soc.* 2013;61(1):67-73.
117. Cruice M, Worrall L, Hickson L, Murison R. Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being. *Aphasiology.* 2003;17(4):333-353.
118. Holland AL, Frattali C, Fromm D. *CADL-2 Communication Activities of Daily Living: Examiner's Manual.* pro-ed; 1999.
119. Swinburn K, Porter G, Howard D. *CAT: comprehensive aphasia test.* London, UK: Psychology Press; 2004.
120. Huber W, Poeck K, Willmes K. The Aachen Aphasia Test. *Adv Neurol.* 1983;42:291-303.
121. Paul DR, Association AS-L-H. *Quality of Communication Life Scale: Manual.* ASHA; 2004.
122. Katz RC, Wertz RT. The efficacy of computer-provided reading treatment for chronic aphasic adults. *Journal of Speech, Language and Hearing Research.* 1997;40(3):493.
123. Brady MC, Kelly H, Godwin J, Enderby P. Speech and language therapy for aphasia following stroke. *Cochrane Database Syst Rev.* 2012;5:CD000425.
124. Roethlisberger FJ, Dickson WJ. *Management and the Worker.* Vol 5: Psychology Press; 2003.
125. Chen Z-Y, Patel PD, Sant G, et al. Variant brain-derived neurotrophic factor (BDNF)(Met66) alters the intracellular trafficking and activity-dependent secretion of wild-type BDNF in neurosecretory cells and cortical neurons. *J Neurosci.* 2004;24(18):4401-4411.

126. Rostami E, Krueger F, Zoubak S, et al. BDNF polymorphism predicts general intelligence after penetrating traumatic brain injury. *PLoS One.* 2011;6(11):e27389.
127. Rostami E, Krueger F, Plantman S, et al. Alteration in BDNF and its receptors, full-length and truncated TrkB and p75 NTR following penetrating traumatic brain injury. *Brain Res.* 2014;1542:195-205.
128. Failla MD, Kumar RG, Peitzman AB, Conley YP, Ferrell RE, Wagner AK. Variation in the BDNF gene interacts with age to predict mortality in a prospective, longitudinal cohort with severe TBI. *Neurorehabil Neural Repair.* 2015;29(3):234-246.
129. O'Keefe LM, Doran SJ, Mwilambwe-Tshilobo L, Conti LH, Venna VR, McCullough LD. Social isolation after stroke leads to depressive-like behavior and decreased BDNF levels in mice. *Behav Brain Res.* 2014;260:162-170.
130. Moretti L, Cristofori I, Weaver SM, Chau A, Portelli JN, Grafman J. Cognitive decline in older adults with a history of traumatic brain injury. *The Lancet Neurology.* 2012;11(12):1103-1112.
131. Lambon Ralph MA, Snell C, Fillingham JK, Conroy P, Sage K. Predicting the outcome of anomia therapy for people with aphasia post CVA: both language and cognitive status are key predictors. *Neuropsychol Rehabil.* 2010;20(2):289-305.
132. Chin LM, Keyser RE, Dsurney J, Chan L. Improved Cognitive Performance Following Aerobic Exercise Training in People With Traumatic Brain Injury. *Arch Phys Med Rehabil.* 2015;96(4):754-759.
133. Piepmeier AT, Etnier JL. Brain-derived neurotrophic factor (BDNF) as a potential mechanism of the effects of acute exercise on cognitive performance. *Journal of Sport and Health Science.* 2015;4(1):14-23.
134. Cramer S, Procaccio V. Correlation between genetic polymorphisms and stroke recovery: analysis of the GAIN Americas and GAIN International Studies. *Eur J Neurol.* 2012;19(5):718-724.
135. Pearson-Fuhrhop KM, Kleim JA, Cramer SC. Brain plasticity and genetic factors. *Top Stroke Rehabil.* 2009;16(4):282-299.
136. van der Lely HK, Pinker S. The biological basis of language: insight from developmental grammatical impairments. *Trends in cognitive sciences.* 2014;18(11):586-595.
137. Hersh D. I can't sleep at night with discharging this lady: The personal impact of ending therapy on speech-language pathologists. *Int J Speech Lang Pathol.* 2010;12(4):283-291.
138. Hinckley J. The piano lesson: An autoethnography about changing clinical paradigms in aphasia practice. *Aphasiology.* 2005;19(8):765-779.
139. Sherratt S, Worrall L, Pearson C, Howe T, Hersh D, Davidson B. "Well it has to be language-related": speech-language pathologists' goals for people with aphasia and their families. *Int J Speech Lang Pathol.* 2011;13(4):317-328.
140. Ryan GW, Nolan JM, Yoder PS. Successive free listing: Using multiple free lists to generate explanatory models. *Field Methods.* 2000;12(2):83-107.
141. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today.* 2004;24(2):105-112.
142. Houghton C, Casey D, Shaw D, Murphy K. Rigour in qualitative case-study research. *Nurse Res.* 2013;20(4):12-17.
143. Sandelowski M. Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *ANS Adv Nurs Sci.* 1993;16(2):1-8.
144. Mays N, Pope C. Qualitative research in health care: Assessing quality in qualitative research. *BMJ: British Medical Journal.* 2000;320(7226):50.

145. McLaughlin E, Lincoln M, Adamson B. Speech-language pathologists' views on attrition from the profession. *Int J Speech Lang Pathol.* 2008;10(3):156-168.
146. Davey A, Arcelus J, Munir F. Work demands, social support, and job satisfaction in eating disorder inpatient settings: A qualitative study. *International journal of mental health nursing.* 2013.
147. Randolph DS. Predicting the effect of extrinsic and intrinsic job satisfaction factors on recruitment and retention of rehabilitation professionals. *Journal of healthcare management/American College of Healthcare Executives.* 2005;50(1):49.
148. Fimian MJ, Lieberman RJ, Fastenau PS. Development and validation of an instrument to measure occupational stress in speech-language pathologists. *J Speech Hear Res.* 1991;34(2):439-446.
149. Breitenstein C, Grewe T, Flöel A, et al. Intensive speech and language therapy in patients with chronic aphasia after stroke: a randomised, open-label, blinded-endpoint, controlled trial in a health-care setting. *The Lancet.* 2017.
150. Babbitt EM, Worrall L, Cherney LR. Who Benefits From an Intensive Comprehensive Aphasia Program? *Topics in Language Disorders.* 2016;36(2):168-184.
151. Winans-Mitrik R, Schumacher JG, Hula WD, Dickey MW, Doyle PJ. Description of an intensive residential aphasia treatment program: Rationale, clinical processes, and outcomes. Clinical Aphasiology Conference; 2013; Tucson, AZ.
152. Frattali CM, Frattali C. Outcomes measurement: Definitions, dimensions, and perspectives. *Measuring outcomes in speech-language pathology.* 1998:1-27.
153. Wallace SJ, Worrall L, Rose T, et al. Which outcomes are most important to people with aphasia and their families? an international nominal group technique study framed within the ICF. *Disabil Rehabil.* 2016:1-16.
154. Tomkins B, Siyambalapitiya S, Worrall L. What do people with aphasia think about their health care? Factors influencing satisfaction and dissatisfaction. *Aphasiology.* 2013;27(8):972-991.
155. Corsten S, Konradi J, Schimpf EJ, Hardering F, Keilmann A. Improving quality of life in aphasia—Evidence for the effectiveness of the biographic-narrative approach. *Aphasiology.* 2014;28(4):440-452.
156. Wenke R, Lawrie M, Hobson T, et al. Feasibility and cost analysis of implementing high intensity aphasia clinics within a sub-acute setting. *Int J Speech Lang Pathol.* 2014;16(3):250-259.
157. Grawburg M, Howe T, Worrall L, Scarinci N. A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia. *Aphasiology.* 2013;27(7):828-848.
158. Grawburg M, Howe T, Worrall L, Scarinci N. Describing the impact of aphasia on close family members using the ICF framework. *Disabil Rehabil.* 2014;36(14):1184-1195.
159. Feinberg L, Reinhard SC, Houser A, Choula R. Valuing the invaluable: 2011 update, the growing contributions and costs of family caregiving. *Washington, DC: AARP Public Policy Institute.* 2011:32.
160. Reinhard SC, Feinberg LF, Choula R, Houser A. Valuing the invaluable: 2015 update. *Insight on the Issues.* 2015;104.
161. Quinn K, Murray C, Malone C. Spousal experiences of coping with and adapting to caregiving for a partner who has a stroke: a meta-synthesis of qualitative research. *Disabil Rehabil.* 2013;36(3):185-198.
162. Fox L, Poulsen S, Clark Bawden K, Packard D. Critical elements and outcomes of a residential family-based intervention for aphasia caregivers. *Aphasiology.* 2004;18(12):1177-1199.

163. Halle MC, Le Dorze G. Understanding significant others' experience of aphasia and rehabilitation following stroke. *Disabil Rehabil.* 2014;36(21):1774-1782.
164. Rundell SD, Goode AP, Friedly JL, Jarvik JG, Sullivan SD, Bresnahan BW. Role of Health Services Research in Producing High-Value Rehabilitation Care. *Phys Ther.* 2015;95(12):1703-1711.
165. Lloyd V, Gatherer A, Kalsy S. Conducting qualitative interview research with people with expressive language difficulties. *Qual Health Res.* 2006;16(10):1386-1404.
166. Ritchie J, Spencer L, O'Connor W. Carrying out qualitative analysis. *Qualitative research practice: A guide for social science students and researchers.* 2003:219-262.
167. Kagan A. Supported conversation for adults with aphasia: Methods and resources for training conversation partners. *Aphasiology.* 1998;12(9):816-830.
168. Dictionary MWO. Milieu n.d.; http://www.merriam-webster.com/dictionary/milieu.
169. Barnett E, Casper M. A definition of "social environment". *Am J Public Health.* 2001;91(3):465.
170. Davidson B, Howe T, Worrall L, Hickson L, Togher L. Social participation for older people with aphasia: the impact of communication disability on friendships. *Top Stroke Rehabil.* 2008;15(4):325-340.
171. Brand C, Barry L, Gallagher S. Social support mediates the association between benefit finding and quality of life in caregivers. *J Health Psychol.* 2016;21(6):1126-1136.
172. Sit JW, Wong TK, Clinton M, Li LS. Associated factors of post-stroke depression among Hong Kong Chinese: a longitudinal study. *Psychol Health Med.* 2007;12(2):117-125.
173. Sit JW, Wong TK, Clinton M, Li LS, Fong YM. Stroke care in the home: the impact of social support on the general health of family caregivers. *J Clin Nurs.* 2004;13(7):816-824.
174. King RB, Shade-Zeldow Y, Carlson CE, Feldman JL, Philip M. Adaptation to stroke: a longitudinal study of depressive symptoms, physical health, and coping process. *Top Stroke Rehabil.* 2002;9(1):46-66.
175. Rombough RE, Howse EL, Bartfay WJ. Caregiver strain and caregiver burden of primary caregivers of stroke survivors with and without aphasia. *Rehabil Nurs.* 2006;31(5):199-209.
176. Creswell JW, Plano Clark VL. *Designing and conducting mixed methods research.* Thousand Oaks: Sage; 2011.
177. Munoz-Plaza CE, Parry C, Hahn EE, et al. Integrating qualitative research methods into care improvement efforts within a learning health system: addressing antibiotic overuse. *Health Research Policy and Systems.* 2016;14(1):1-10.
178. Cherney LR, Patterson JP, Raymer A, Frymark T, Schooling T. Evidence-based systematic review: Effects of intensity of treatment and constraint-induced language therapy for individuals with stroke-induced aphasia. *Journal of Speech, Language and Hearing Research.* 2008;51(5):1282.
179. Robey RR. A meta-analysis of clinical outcomes in the treatment of aphasia. *Journal of Speech, Language and Hearing Research.* 1998;41(1):172.
180. Qu H, Shewchuk RM, Chen YY, Richards JS. Evaluating the quality of acute rehabilitation care for patients with spinal cord injury: an extended Donabedian model. *Qual Manag Health Care.* 2010;19(1):47-61.
181. Lemke S, Moos RH. Measuring the social climate of congregate residences for older people: Sheltered Care Environment Scale. *Psychol Aging.* 1987;2(1):20-29.
182. Moos RH. Context and coping: Toward a unifying conceptual framework. *Am J Community Psychol.* 1984;12(1):5-36.
183. House JS, Landis KR, Umberson D. Social relationships and health. *Science.* 1988;241(4865):540-545.

184. Heaney CA, Israel BA. Social networks and social support. In: Glanz K, Rimer BK, Viswanath K, eds. *Health behavior and health education: Theory, research, and practice*. 4th ed. San Francisco: Jossey-Bass; 2008:189-210.
185. Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: measuring the positive legacy of trauma. *J Trauma Stress.* 1996;9(3):455-471.
186. Danhauer SC, Case LD, Tedeschi R, et al. Predictors of posttraumatic growth in women with breast cancer. *Psychooncology.* 2013;22(12):2676-2683.
187. McDonough MH, Sabiston CM, Wrosch C. Predicting changes in posttraumatic growth and subjective well-being among breast cancer survivors: the role of social support and stress. *Psychooncology.* 2014;23(1):114-120.
188. Grace JJ, Kinsella EL, Muldoon OT, Fortune DG. Post-traumatic growth following acquired brain injury: a systematic review and meta-analysis. *Front Psychol.* 2015;6.
189. Senol-Durak E, Ayvasik HB. Factors associated with posttraumatic growth among myocardial infarction patients: perceived social support, perception of the event and coping. *J Clin Psychol Med Settings.* 2010;17(2):150-158.
190. Hallam W, Morris R. Post-traumatic growth in stroke carers: a comparison of theories. *Br J Health Psychol.* 2014;19(3):619-635.
191. Mack J, Herrberg M, Hetzel A, et al. The factorial and discriminant validity of the German version of the Post-traumatic Growth Inventory in stroke patients. *Neuropsychol Rehabil.* 2015;25(2):216-232.
192. Gangstad B, Norman P, Barton J. Cognitive processing and posttraumatic growth after stroke. *Rehabil Psychol.* 2009;54(1):69-75.
193. Brown K, Davidson B, Worrall LE, Howe T. "Making a good time": the role of friendship in living successfully with aphasia. *Int J Speech Lang Pathol.* 2013;15(2):165-175.
194. Fotiadou D, Northcott S, Chatzidaki A, Hilari K. Aphasia blog talk: How does stroke and aphasia affect a person's social relationships? *Aphasiology.* 2014;28(11):1281-1300.
195. Grawburg M, Howe T, Worrall L, Scarinci N. Third-party disability in family members of people with aphasia: a systematic review. *Disabil Rehabil.* 2013;35(16):1324-1341.
196. Varadhan R, Segal JB, Boyd CM, Wu AW, Weiss CO. A framework for the analysis of heterogeneity of treatment effect in patient-centered outcomes research. *J Clin Epidemiol.* 2013.
197. Fondacaro MR, Moos RH. Social support and coping: a longitudinal analysis. *Am J Community Psychol.* 1987;15(5):653-673.
198. Moos R, Igra A. Determinants of the Social Environments of Sheltered Care Settings. *J Health Soc Behav.* 1980;21(1):88-98.
199. Crooke PJ, Olswang LB. Practice-Based Research: Another Pathway for Closing the Research-Practice Gap. *J Speech Lang Hear Res.* 2015;58(6):S1871-1882.
200. Horn SD, DeJong G, Deutscher D. Practice-Based Evidence Research in Rehabilitation: An Alternative to Randomized Controlled Trials and Traditional Observational Studies. *Arch Phys Med Rehabil.*93(8):S127-S137.

Appendices

Appendix A: Link to published manuscript – Incorporated as Chapter Two

Structure, Processes, and Retrospective Outcomes From an Intensive Comprehensive Aphasia Program

Am J Speech Lang Pathol. 2015 Nov;24(4):S854-63. doi: 10.1044/2015_AJSLP-14-0164

APPENDIX B: LINK TO PUBLISHED MANUSCRIPT – INCORPORATED AS CHAPTER THREE

WHO BENEFITS FROM AN INTENSIVE COMPREHENSIVE APHASIA PROGRAM?

Topics in Language Disorders: April/June 2016 - Volume 36 - Issue 2 - p 168–184.doi: 10.1097/TLD.0000000000000089

APPENDIX C: LINK TO PUBLISHED MANUSCRIPT – INCORPORATED AS CHAPTER FOUR

CLINICIAN PERSPECTIVES OF AN INTENSIVE COMPREHENSIVE APHASIA PROGRAM. - PUBMED - NCBI

TOP STROKE REHABIL. 2013 SEP-OCT;20(5):398-408. DOI: 10.1310/TSR2005-398

APPENDIX D: DOCUMENTATION OF ETHICS APPROVAL FROM NORTHWESTERN UNIVERSITY FOR DATABASE ANALYSIS

Institutional Review Board Office
Northwestern University

Biomedical IRB
750 North Lake Shore Drive
Suite 700
Chicago, Illinois 60611
312-503-9338

Social and Behavioral Sciences IRB
600 Foster Street
Chambers Hall, Second Floor
Evanston, Illinois 60208
847-467-1723

09/4/2013

Ms. Edna Babbitt

RIC Center for Aphasia Research & Treatment 345 E Superior St #1353

Chicago IL 60611

IRB Project Number: STU00077762

Project Title: Analysis of Outcomes from an Intensive Comprehensive Aphasia Program

Project Sites:

Rehabilitation Institute of Chicago (RIC)

Northwestern University (NU)

Submission Considered: New Submission **Submission Number:** STU00077762
Study Review Type: Expedited
Review Date: 9/3/2013
Status: APPROVED **Approval Period:** (9/3/2013 - 9/2/2014)

Dear Ms. Babbitt,

The IRB considered and approved your submission referenced above through 9/2/2014. As Principal Investigator (P.I.), you have ultimate responsibility for the conduct of this study, the ethical performance of the project, and the protection of the rights and welfare of human subjects. You are required to comply with all NU policies and procedures, as well as with all applicable Federal, State and local laws regarding the protection of human subjects in research including, but not limited to the following:

- Not changing the approved protocol or consent form without prior IRB approval (except in an emergency, if necessary, to safeguard the well-being of human subjects).
- Obtaining proper informed consent from human subjects or their legally responsible representative, using only the currently approved, stamped consent form.
- Promptly reporting unanticipated problems involving risks to subjects or others, or promptly reportable non-compliance in accordance with IRB guidelines.
- Submit a continuing review application 45 days prior to the expiration of IRB approval. If IRB re-approval is not obtained by the end of the approval period indicated above, all research related activities must stop and no new subjects may be enrolled.

IRB approval includes the following:

Written Consent Form/Consent Form and Authorization for Research:

Name

Consent form (version date 08.27.2013).docx

Waiver of Consent: A Waiver of Consent was granted for the retrospective chart review component of this project in accordance with section 45CFR46.116d(1-4)

HIPAA: A HIPAA Exception - Limited Data Set was granted for this project in accordance with section 42CFR 164-512 (I) 2(ii) of the HIPAA Privacy Rule and with Northwestern University's HIPAA Research Policy.

Protocol Document:

Name

Chart review protocol (version date 08.20.2013).docx

For more information regarding IRB Office submissions and guidelines, please consult http://irb.northwestern.edu. Thishttp://irb.northwestern.edu. This Institution has an approved Federal wide Assurance with the Department of Health and Human Services: FWA00001549.

APPENDIX E: DOCUMENTATION OF ETHICS APPROVAL FROM NORTHWESTERN UNIVERSITY FOR QUALITATIVE INTERVIEWS

Institutional Review Board Office
Northwestern University

Biomedical IRB
750 North Lake Shore Drive
Suite 700
Chicago, Illinois 60611
312-503-9338

Social and Behavioral Sciences IRB
600 Foster Street
Chambers Hall, Second Floor
Evanston, Illinois 60208
847-467-1723

03/13/2014
Ms. Edna Babbitt
RIC Center for Aphasia Research & Treatment 345 E Superior St #1353
Chicago IL 60611

IRB Project Number: STU00090802
Project Title: Consumer Perspectives from an Intensive Comprehensive Aphasia Program (ICAP)
Project Sites: Rehabilitation Institute of Chicago (RIC)

Sponsor Information (Grant #, if applicable):

Submission Considered: New Submission **Submission Number:** STU00090802
Study Review Type: Expedited
Review Date 3/13/2014
Status: APPROVED **Approval Period:** (3/13/2014 - 3/12/2015)

Dear Ms. Babbitt,

The IRB considered and approved your submission referenced above through 3/12/2015. As Principal Investigator (P.I.), you have ultimate responsibility for the conduct of this study, the ethical performance of the project, and the protection of the rights and welfare of human subjects. You are required to comply with all NU policies and procedures, as well as with all applicable Federal, State and local laws regarding the protection of human subjects in research including, but not limited to the following:

- Not changing the approved protocol or consent form without prior IRB approval (except in an emergency, if necessary, to safeguard the well-being of human subjects).
- Obtaining proper informed consent from human subjects or their legally responsible representative, using only the currently approved, stamped consent form.
- Promptly reporting unanticipated problems involving risks to subjects or others, or promptly reportable non-compliance in accordance with IRB guidelines.
- Submit a continuing review application 45 days prior to the expiration of IRB approval. If IRB re-approval is not obtained by the end of the approval period

indicated above, all research related activities must stop and no new subjects may be enrolled.

IRB approval includes the following:

Written Consent Form/Consent Form and Authorization for Research:

Name

Phase 2 IRB consent form PWA 030414 v.2.docx

Protocol Document:

Name

Babbitt protocol v.2.docx

Recruitment Materials (Note- the investigator is responsible for complying with applicable departmental or NU policies regarding use of bulk e-mail for recruitment purposes):

Name

Phase 2 Aphasia Friendly Info Sheet EB.docx

Interview Scripts:

Name

Interview Questions RIC IAP.docx

For more information regarding IRB Office submissions and guidelines, please consult http://irb.northwestern.edu. This Institution has an approved federal wide Assurance with the Department of Health and Human Services: FWA00001549.

THE UNIVERSITY OF QUEENSLAND

Institutional Human Research Ethics Approval

Project Title:	An Analysis Of Outcomes From An Intensive Comprehensive Aphasia Program
Chief Investigator:	Miss Edna Babbitt
Supervisor:	Prof Linda Worrall, A/Prof David Copland, Prof Leora Cherney
Co-Investigator(s):	Prof Linda Worrall, A/Prof David Copland, Prof Leora Cherney
School(s):	School of Health & Rehabilitation Sciences
Approval Number:	2013001350
Granting Agency/Degree:	PhD
Duration:	31st October 2016

Comments:

Note: if this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:
Medical Research Ethics Committee
This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:
Professor Bill Vicenzino
Chairperson
Medical Research Ethics Committee

Signature  Date 13/11/2013

APPENDIX G. SAMPLE SCHEDULE WITH EXAMPLES OF APHASIA TREATMENT APPROACHES

	Session	Evidence-Based Treatment Examples (non-inclusive)	Non-Evidence-Based Treatment Examples (non-inclusive)
9:00	Constraint Induced Language Therapy	Constraint Induced Language Therapy (CILT)	
10:00	Reading/ Writing Group		Reading tasks and materials geared to person's level and interests in group setting
		Writing: ACT/CART	Writing tasks and materials geared to person's level and interests in group setting
11:00	Individual	RET VNeST TUF Phonomotor SFA (nouns and verbs)	Individualized treatments based on clinician judgment and participant deficits, goals, and interests
12:00	Lunch		
1:00	Computer	AphasiaScripts ORLA	Other commercially available software programs developed specifically for aphasia
2:00	Individual	RET VNeST TUF Phonomotor SFA (nouns and verbs)	Individualized treatments based on clinician judgment and participant deficits, goals, and interests
3:00	Conversation Group	Discourse management strategies	Activities and goals related to social exchanges were based on participants' skills and interests

ACT = Anagram and Copy Treatment
CART = Copy and Recall Treatment
ORLA = Oral Reading for Language in Aphasia
RET = Response Elaboration Training
SFA = Semantic Feature Analysis
SVO = Subject Verb Object
TUF = Treatment of Underlying Forms
VNeST = Verb Network Strengthening Treatment

Relationships

1.1 Meeting other PWA: admiration/feelings
1.2 Social interactions: conversations, meals, exercises
1.3 Helping/Supporting
1.4 Forming bonds/relationships
1.5 Family: Meeting other Family
1.6 Family: Social interactions
1.7 Family: Help/support each other
1.8 Family – providing support to PWA

Outcomes

2.1 General Improvements
2.2 Improvement in general ability & tasks: get back into life e.g., dressing oneself
2.3 Physical ability improvements: Stamina & strength
2.4 Conversation improvements
2.5 Speech improvements
2.6 Writing improvements
2.7 Reading improvements
2.8 Psychosocial
2.9 Technology Use

Treatment

3.1 General comments
3.2 Intensity: of therapy, tired?
3.3 Preference: for certain sessions
3.4 Length: structure of program
3.5 Speech-Language Pathologist: relationship, skill of SLP,
3.6 Reflection/Evaluation: satisfaction, expectations, general, learning
3.7 Post-Program
3.8 Comparison to previous TX

APPENDIX I: EXAMPLE OF CODED INTERVIEW TRANSCRIPT

Participant ID and comment #	Transcription	Code Name	Code #
P01 01	**Do you have examples or um like specific things you can think of in terms of** W: that um show improvement **Where you've seen the progress** W: I think I know the kids mentioned this too is that um he speaks in more complete sentences than he did before I know they worked a lot on verbs and he would say uh well before it was just a word or two but he gets out a lot of um you know longer sentences now yeah a couple sentences sometimes in a row which is like whoa before I used to count when he would say a bunch of oh my gosh that was 11 words so that is a that's the biggest thing I see **OK**	Speech improvements	2.5
P01 02	W: and he doesn't seem as afraid to talk before it seemed like you wouldn't say anything B: yeah W: but now you seem like you're more willing to just do it you know that's a big B: I'm hoping W: mhmm **You agree with that** B: ah yes yes I am yes I do	Psychosocial	2.8
P01 03	**Do you feel different about talking?** B: / I I I've always had but never I didn't really click to me that could be s you know I used to be when I first come [writes Page 3 bottom] my s- n-/ no my song? is nowhere and there slowly I xxx but now I feel like as hard? I'm really going up	Speech improvements	2.5
P01 04	**So from how long this is when you had your stroke** B: yeah x **And is this about 10 months?** B: xx exactly [writing] ///probably **Oh OK so last year** B: and that was like nothing x **So this is about a year** B: yeah **OK it felt like noth** B: xx yeah I yeah and I was I know I thought I doing great but it's like uh you know it's all I can do is is do anything dadada xx so it's kind of um// [writing] and here it's like/ is is I feel it's been going great W: I think he was much very encouraged aft- you know with the program that he was that he actually was making progress because the speech progress was so much slower than like his walking and everything he was doing so much better physically but the speech was slow to come	Psychosocial	2.8
P01 05	and I think he reali- that gave him hope that yeah this can get better and this you know this is getting better before it was like i-n- why bother it's not getting there W: but I think this is really been an encouragement don't you think B: yeah yeah W: this it shows B: Well I I think you know just gotta be hopeful and just say // that you could know that OK that's you're hoping that B: it'll one day hopefully one day you know you go and	Psychosocial	2.8